

CFS - My Companion

by bethany yagci

02/15/10

IT WAS NEW YEARS EVE, the last day of 1985. I was 24, three years into marriage, with a son who just turned one. We had just moved to the States the month before Thanksgiving. We weren't ones to celebrate holidays, weren't into drinking. I wasn't into special cooking, I was quite happy and content. IT WAS JUST A NORMAL DAY... OR SO I THOUGHT.

The pain hit my abdomen acutely about 7 pm. I lay on the couch writhing in pain until I fell asleep. The next day I remained generally uncomfortable until around 7 pm and the pain hit again. The third day I experienced the same thing. This time I went to the local clinic for emergency care. I was seen by a young intern lady who saw my husband was a foreigner who spoke no English, looked at our last name and spewed off instructions to avoid spicy food. Her stereotyping of us was erroneous. I was an American married to a Turk from Istanbul. We never ate spicy food to begin with. That was my introduction to the medical response that would become more familiar in years ahead. I went home confused.

The illness remained and has never left me from that first day to this day, though symptoms have changed in number and severity many times. My aunt suggested a doctor and I went to him and was diagnosed with Endometriosis. He advised I should have another child soon if I wanted one, and treated me with a freezing of the uterus. Later I did have another child, which was neither planned nor unplanned. I had only pain on my mind in those days. Further along I came to know that it was a wrong diagnosis.

During 1986 – 87 I had only a few symptoms: severe abdominal pain, constant fatigue, lack of energy, loss of cognitive focus, and trouble walking began from the very beginning. During my pregnancy in 1987 I was feeling better in some ways generally speaking, but I still had severe abdominal pain and pressure, which grew worse as the baby grew and added his own pressure to it. I would go to my ob-gyn and she would tell me how fine my baby was doing and I would complain and go home discouraged. I was happy for the baby, but I wanted somebody to care how I was doing, or better yet, fix it. By the time I was 7 months along my husband took me back to Turkey, where his relative doctor took over the delivery of the baby. I was in so much pain by the 7th month that I began to pray daily for the baby to be born early (not a wise thing to do as I see now). I went into labor at 8 months. It was a very primitive experience, as my first one in a state hospital had been, and afterward they didn't bother to check my blood pressure. They did say the baby was cold, and swept him off to a children's hospital where I waited a day to be reunited with him. After a day and night in that nightmare, where I had to remove a tube from his nose and replace it whenever I took him from the incubator to nurse him – there was no nurse or doctor on duty at all to show me anything – we were released the next day to go home.

I spent the next month having black-outs to where I could see clearly directly in front of me, but if I turned my head the slightest bit left or right, I could only see black. I went back to the relative doctor who laughed at me and said I was probably pregnant again, failing to check my blood pressure again. My husband agreed to let me go early to my parents in Germany, where I was immediately put on low blood pressure medication. After 2 weeks he caught up with me, and the next month we were back in the States where I saw my ob-gyn again. She was convinced to do a laparoscopy right away, but it revealed nothing. What I liked about her was that she never made fun of me or put me down, but she at least tried to do something, even if it didn't work. She was a sensible and intelligent female doctor who gave me some sense of stability during a time of great confusion and pain.

After that, during 1988, I went into my first crisis period. My symptoms blossomed that year from the few into a multitude. I was overwhelmed and still without a diagnosis. I had a new baby and my arms were too weak to hold him. If I were standing I was terrified I would drop him. I was severely sensitive to clothing, light, heat, touch, etc. Symptoms would fluctuate and change. I couldn't tell someone I had a headache because while I was saying it, it might change, and it would be awkward. (You had a headache a second ago but now you have a shooting pain in your leg, followed by tinnitus? Unhuh...) I was on my feet, not bedridden but housebound for the most part. I had such severe symptoms, however, that it was possibly even worse than when I was bedridden later on. I had a great deal of trouble going to a store, walking or standing in line particularly. I began attending church then, only because it was right across the street. The pastor nor any of the people ever visited me, though they were friendly. Once one of the young people came up to me to ask me if I wanted to go bowling! Instinctively I looked at the oldest lady in the church, in her 90's, and actually wondered why they didn't ask her. I couldn't imagine what in the world to answer. I just said no. I spent years trying to figure out what to answer people or say to them – especially how to answer that most horrible question “How are you?”

It was during 1988–89 that I arranged to be seen at the Mayo Clinic in Jacksonville, Florida. I spent a week getting a complete work up. Basically nothing came of it. I don't want to do them an injustice as I don't remember everything, but even the intestinal tests revealed nothing and the main part I remember is that I was told not to eat standing up (I spent all my time in a chair or bed anyway). **All the expense and still no diagnosis.** The ironic part is that I fell asleep while waiting for the doctor in his office that first day. It was almost begging for a 'fatigue' diagnosis. (In those days I didn't yet have insomnia.) I saw one other doctor during that time, whether before Mayo or after, I do not know. At any rate, she came into the room as if announcing a tragedy, and told me I had Epstein Barr. When I didn't react significantly she said “That can go to your brain, you know!” I thought, 'well finally someone sees something wrong... I've only known it for years already and been walking around with this brain till now.' She put me on a round of antibiotics. The titer supposedly came down **but I didn't feel in the least way any different.** I called after that to make an appointment and the receptionist started screaming at me over the phone “The doctor does not want to see you again! The doctor does not want to see you!” That was probably my strangest medical experience. She was a nice doctor. I was confused.

During that time I was pregnant again and less than 80 pounds. Because of severe abdominal pain I would eat 2 weeks gradually decreasing and eliminating, and eat maybe only one thing like pancakes or bread for the next 2 weeks until the pain eased up. I cycled like that for a good while. At that time we moved north to the Philadelphia area. The car trip was utterly miserable; I felt abused traveling with only my window barely cracked and no air conditioning with outside temperatures of 95 to 100 degrees Fahrenheit when I was heat intolerant, needing to eat and drink by 11 am or at least noon in those days and every exit being passed up until 2 pm. I was in way too much pain. We had a big fallout at that time. My marriage was finally suffering. I think CFS already makes you feel abused on the inside because of your body's rejection of itself. Outside stress only magnifies the situation. I begged to take the kids to my parents and stay in Germany for awhile. In Germany I was again put on low blood pressure medication. However, I soon miscarried, in an uncommon way. The baby entire *en sac* had fallen to where it was partially out. I was given the choice to try and put him back and sew me up. The elderly head doctor kept shaking his head over me. He said there was too much fluid. He didn't seem to know why. Because of the invisible pain I lived with daily, I chose to let the baby go. I still regret it. I lived in pain either way.

I stayed in Germany for one year. I could probably count on one hand the number of times I went out other than to doctors. I had a throat infection once. It was like the strep throat of all strep throats. My throat was blistered all up and down. My sister took me to see the doctor to translate for me and he took one look at my throat and was positive it must be Mononucleosis. The test came back negative. Another time I went to their family doctor. He was the same one who

had once put me on blood pressure medication. My mother told him how sick I was. As we were in the office, Mom told me a joke (unusual for her—probably trying to distract me) and I laughed right when he was passing the hall. He looked at me with a strange expression. I returned home from that visit with a diagnosis of psychological something or other... What is ironic is that people have always put me down for not being someone who smiles, jokes, or laughs easily. But it is true that the medical profession is geared toward the acutely ill, who can stop living for awhile, and not the chronically ill, who have to get on with living one way or another, day in and day out, and shouldn't be derided for how they do it.

It was good for me to be with my mother because she was always a great detective, and I did make progress with her. I started on protein powder, she put all of my food through the food processor, and I started taking digestive enzymes that year. My strength increased tremendously. However, just before I left, I not only developed an allergy to the soy protein, but all of my allergies began with that. I moved back to my husband, and went into my second crisis time during 1991 – 1993. I stopped eating processed food, but increased and kept taking the enzyme supplements to this day. The enzymes were instrumental in the reduction of abdominal pain. However, they did not stop the crisis, and I became bedridden and housebound during those years. It was in 1992, seven years after initial onset, that I was diagnosed with severe Chronic Fatigue Syndrome by my doctor in New Jersey.

This doctor was a good doctor, who didn't put me down in any way. It can always be said that more could have been done, but those were days where little was known, and I was perhaps not good at describing my life at home, that there were times when I couldn't go downstairs and had to wait for my kids to come home to get me something from the kitchen to eat or drink. Actually I could have made it downstairs if I had to, but then how or when to get back upstairs, and there was no furniture to sit or lay down on. Life was hard but I tried to be brave. I always thought the doctors had the answers and tried to follow any instructions they gave me. During that time, probably by his recommendation, I went to Dr. Cheney & Dr. Lapp's CFS clinic. That was another long trip by car, in so much pain that when my husband said he couldn't drive any longer, I took over the wheel and drove myself on cruise control... I barely had strength to get it up to cruise, and don't know how I could have possibly handled an emergency...but one thing I knew – I couldn't bear the pain of sitting in one position for hours while he slept... I needed to get there, stretch out, lay flat, and rest. Nothing much came of that visit. I was disappointed. I don't remember why... perhaps I couldn't do the recommendations... was too tired to follow through... couldn't remember what I was told... or there just wasn't anything to recommend in those days of any real value that we could afford. Whatever the case, it seemed to me to have not worked. Back with my NJ doctor, I asked to try Diflucan and he allowed it. From the first pill, my system was hit like a bolt. I obviously had a Candida problem. That and the enzymes were, so far, the only real help for me during my years of illness. For my allergies, I went through a \$2,000 panel, covered by insurance, which my husband threw in the trash a day or two after I received it. So I got no benefit from that enterprise either. I hadn't had the energy (having to recover from my trip out to the doctor) to look at it, so he assumed it wasn't important... as the story goes.

The start of Diflucan and the Candida diet, which I did under a British nutritionist specializing in the treatment of overgrowth of Candida, seemed to bring me out of that crisis and my bedridden state slowly but surely. I have never been back that way again, no matter how I may struggle with symptoms daily or am threatened at times to relapse. I came back to 'life' during 1994. I signed up for classes and started to drive a second car to school. During that time, I was still only just beginning to recover, so I was still having sharp dagger pains in my head and legs mainly, having muscle paralysis in bed, and on top of brain fog and confusion, having times of my mind going blank. I wore dark glasses in class, suffered the smell of the markers used, and the smoking at the doorway entrances, and integrating socially.

Once I had an incident when I was driving down the highway... I apparently put my foot on the brake suddenly, and the

car behind me was lucky he wasn't any closer to me. My mind had gone blank and I couldn't remember if I had my foot on the gas or the brake, or which was which. I knew what I was doing was risky, but I knew I couldn't bear for my life to stay as it was, and **nobody was helping me to change it**. I got my schooling done and filed for divorce. I left the state when they allowed me to, and the rest is history. Right or wrong, I took my life into my own hands, because it was the only way. There was no medical help. There was no social help. There was no help at all for a person with CFS.

I have now, in 2010, been sick for as many years as I have been well, exactly half of my life. They were what should have been some of my best years – late 20's, 30's, and 40's. I have dealt with the usual isolation, rejection, ridicule, arrogance, neglect, and abuse from people of all kinds – family, friends, strangers, churches, doctors, nurses, etc – even to this day.

There are also those few that stand out who were especially good, being there at the right time. One friend of the family, a man who has passed on from this life, called me twice during my bedridden state, and I will never forget the kindness in his voice. I cannot say if it was with any understanding of my condition, but it was the compassion I desperately needed during those awful years. The isolation I felt, in spite of having a husband and young children, was overwhelming. The family lived around me as if I were a piece of furniture. And so it seemed that I was. I stared at the four plain white walls and the bare ceiling. I prayed. Life was passing me by as if I didn't exist. My emotional and spiritual state was expressed in one special dream I had at that time.

I saw myself sitting in a chair behind a glass wall. It was like a tunnel, but as if in a gradual circular ring outside of life. People were passing by this way and that way directly in front of me. They were in the process of living their lives. I banged on the glass desperately to try and get them to notice me, but they never looked at me. They couldn't hear me, never looked up, paid no attention. I looked to my left and there was another person far away down the line sitting in a chair like me. I looked to my right and again there was someone in a chair but too far away. Finally I looked up. The warm sun was shining beautifully down on us who were sitting in this strange isolation. Though it was like a tunnel, it was not closed at the top, nor was it dark. You would have thought that everything was normal by looking up. I knew it to be from God saying to me *'You might feel alone, but there are others, and besides that, I am here looking out for you in warm love from above. It's going to be okay.'*

CFS has been a hard companion to have with me day and night. I can't say I will ever get used to her or appreciate her. I can say that I can count on her, and that in spite of seeming to be lacking in mercy, she hasn't killed me. Twice I thought I was dying – during both of my crisis times. I can't say I haven't been healed or cured, as I'm now at a completely different level from days gone by – nor can I say I have been healed or cured, as I continue the daily struggle of life with CFS-ME.

I AM LIVING A PRETENSE OF NORMALCY TO FIT IN WITH THE NORMAL WORLD WHEN EVERYTHING WITHIN ME IS FIGHTING AGAINST IT DAY AND NGHT... THERE IS NOTHING NORMAL ABOUT CFS. TRYING TO LIVE IN THE HEALTHY WORLD IS LIKE BEING A FISH SWIMMING UPSTREAM, AGAINST THE NORMAL FLOW, AGAINST THE TIDE. YOUR BODY FEELS AS IF IT'S FIGHTING AGAINST ITSELF, THE FIGHT OR FLIGHT STRUGGLE DOESN'T END, REST IS ONLY A FOUR LETTER WORD, PRODUCING LITTLE BLESSING BUT SOMETHING THAT HAS TO HAVE ITS WAY ANYWAY.

STILL I HAVE A DAILY HOPE THAT I WILL DO BETTER TODAY THAN I DID YESTERDAY, I WILL MAKE SOME SMALL PROGRESS, THE RESEARCHERS AND SCIENTISTS WILL FIND SOME CURE, MY GOD WILL FORCE A HAND OR A HEART AND PROVIDE COMPASSION FOR MY COMPANION CFS AND ME.