

In 1998, I was working as a temp in Minneapolis, MN. The business was closing that warehouse and had a deadline in which to vacate it. The situation was stressful, as the person who was to train me, suddenly quit. I was left on my own, doing an unfamiliar job. To make matters worse, I was unable to contact my supervisor. Things hit the fan when she came in one day, and I was assisting another employee, thinking it was better than doing nothing; I was being paid. She yelled at me to get to work. I am not one who loses my temper easily, but I had reached my limit. I let her have it. (Being a temp (temporary employee) is one of the most demeaning occupations, one will ever encounter.) I told her I would work out the week, but then I was through.

That Friday, I went home. I did not know it was the last day of my employed life. The next day was my birthday; I was 43 years old. The following week, I became suddenly very weak, ill, and exhausted. I had to apply for government disability. There had been warning signs before this. I had begun to have odd symptoms in 1992: (dizziness, balance problems and vertigo), and was first diagnosed with fibromyalgia. In 1998, I was diagnosed with CFIDS as well. I was told that, without intervention, in five years, I would sit in a chair. I found a knowledgeable doctor in 2000, Dr. Chris Foley in St. Paul, MN. He is a consulting doctor, does not take insurance, and is not cheap. He is the only one who has been able to help me, and he works with me to keep costs down. Nevertheless, I am not able to take all of the treatment regimen he says I need. He also has many tests he would like to perform, but I don't have the money.

It is eleven years later: eleven years of constant pain, fatigue, weakness, and exhaustion. I am still not able to work. I now have cognitive impairments, which began suddenly that summer of 1998. I was a writer, a typesetter, a proofreader; I could type eight hours a day, at 71 wpm, with very few mistakes. Suddenly, I could not find words, substituted the wrong words, mixed up the sequence of words and my short-term memory was gone. There is also no concentration. Repeatedly, throughout the day, I forget what I am doing or saying. My days of multi-tasking are over; now I have "one-channel only". I can attend to only one incoming stimulus at once.

Dr. Foley told me that CFIDS is also a hypersensitivity syndrome. I now am very susceptible to sensory overload and quickly overwhelmed by too much activity, good or bad. I also have a much lower pain threshold. I can no longer scrape ice off car windows or shovel snow. On bad days, talking on the phone exhausts me.

I now have frequent low-grade infections; headaches, skin pain and odd skin sensations like tingling, buzzing, numbness; burning feet; sore throats, blurred vision, heart palpitations, air hunger, cold sores, itching, stiffness and pain throughout my body. Neck pain and stiffness is severe and requires physical therapy and pool therapy. My balance is bad. I have intermittent dizziness and light-headedness. I also have IBS, leaky gut syndrome, heartburn and acid reflux. (I changed my diet in 1992 on the advice of my doctor and stopped eating gluten and dairy foods. That helped a little.)

One cannot "plan ahead" with CFIDS. Each day is different and unpredictable. CFIDS can change suddenly. Like a cruel joke, I may wake feeling fairly good. An hour later, I am weak, having heart palpitations and have to lie down when overcome with sleepiness. On a good day, I may have an hour or two of unexpected energy in the

afternoon. I will use it like a miser, for the most valuable things: oil painting or writing. The next day I am back in my chair, exhausted, weak, nauseous. There is no rhyme to these few days of energy. I may wait weeks or months for another day like that. They are like gold now.

CFIDS – Marie Tyburec

For the first few years after getting sick, I could not paint at all. Imagine my triumph at being able to paint again! Recently, I was also able to sing in a choir's Easter pageant that lasted an hour, something I could not do in the early days of sickness.

I keep in contact with Dr. Foley. Each year, it seems he adds more to my diagnoses list. Now it's insomnia. I already had a sleep disorder, (sleep apnea), and may have delayed sleep phase syndrome.

I keep a concise health log to look for any patterns of cause and result, to help with research, and to share with Dr. Foley when we have a phone consultation. Progress has been painfully slow. About a year ago, he put me on NT Factor Energy from Researched Nutritionals, which works on the cellular level. I am having some improvement in endurance, but again, it is random.

Before I got sick, I had goals. My standards have always been high. I had earned a BFA in art at the University of South Dakota in 1985. In 1987, I moved to the Twin Cities to pursue a career in music and continue painting, with the goals of showing and selling my work, and performing and recording professionally. The city, too, was stressful, but it gave me new life. Things looked more possible there. I took two years of voice lessons from a professional jazz flutist and vocalist. She told me "I had it!".

I was derailed by an unscrupulous man and went through a traumatic experience in 1994, which I am sure exacerbated the odd symptoms that were beginning and hastened the full-blown attack of CFIDS.

Finally earning SSDI, which took 13 months, resulted in my move back to small-town South Dakota, a place where there is no community of artists, no cultural outlets and no museums. (Try living on \$847.00 a month.) Forget the stereotype of people on welfare sitting on couches eating Doritos – most people in my situation desperately want their lives back! (We unwilling welfare recipients feel consigned to living in noisy, dirty, government-subsidized apartment buildings in bad neighborhoods, going to food shelves and getting dirty looks from people when we park in handicapped parking spots. Added to this insult, we don't have the money to buy doctors' services, buy high-quality food, or high-grade nutraceuticals that are our best hope for improvement. See www.minnesotanaturalmedicine.com) (Medicare does not cover this specialized care or products.)

We can't throw pills at this disease. I am not interested in treating the symptoms. I will not take any more prescription drugs; indeed, Dr. Foley and I agree that I need to eventually get off the two that I am on. They hinder what he is trying to do, and side effects are not small. We must know the cause(s) and research multi-pronged approaches to treatment.

I want a normal life, whatever that is. A husband would be nice, and the energy to enjoy a life with him. Who would marry me now? (I feel consigned to a two-room apartment in a small town on the edge of nowhere with four cats who need me, but they

aren't great talkers.) My goals have not changed: I want to be a premiere, innovative fine artist who sells and shows her work and a professional singer, and published writer. What has changed is my physical and mental ability to do them. I can't express to you the magnitude of what I have lost.

This is not a life! I tell Dr. Foley, if I could have back 30 percent of my functioning I would be thrilled. I ask God to help me regain the facility I lost when I got sick. I can't work at art for long periods, when I can work at all. I recently sent my portfolio of 20 paintings on CD to a Sioux Falls Art Gallery. They are interested and will review it soon. It inspires me to keep painting, to not give up. (I would be glad to mail you a CD of my paintings, if you like.)

CFIDS – Marie Tyburec

If I can help in any way, with research for this awful, life-robbing disease, I will do it! My only constraints are financial and health limits. They say, "When you have your health, you have just about everything!" I wonder what the opposite is.

I refuse to give up. I am almost 54, single, and am surrounded by people who don't know how sick I am. Some don't believe I am sick. A worker in a medical clinic in St. Paul said to me, "I wish I had time to be sick." The emotional fallout is huge. I have a brother who told me to "get a job." My social life? What social life? This is a town of 760, near a town of 1300. The people my age are gone or divorced; certainly there are no like-minds here, no artists with big ambitions, no people with vision.

Each day is an endurance test. The doctor can't tell me if I will get well. Call me or write to me if I can answer any of your questions. I would even come to meet with you, if that were possible, to tell you the nightmare that CFIDS is!

Marie Tyburec