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Up The Down Staircase: Work & Fibromyalgia



The following is a "Letter to the Editor", reprinted in the Spring 2000 issue of *Fibromyalgia Frontiers*, which raises many important issues relevant to working individuals with fibromyalgia.

[February 19, 2000] During the past few years, I have read with interest numerous articles in *Fibromyalgia Frontiers* about how people have had to reorder their lives after giving up their employment or other regular daily activities. However, there is a related but less frequently discussed issue which I would very much appreciate reading and learning more about.

I suspect that there is an even larger group of people who, like myself, suffer from FM, but not to the point where they/we can no longer work. Instead, because we may be the sole wage-earner or larger financial contributor, we find ourselves giving up almost everything except our work, in order to survive. Our FM is not severe enough to justify disability retirement or the equivalent thereof, nor can we afford to work part-time.

Instead, we end up giving up the few, precious hours in the evening and on weekends and holidays which others without FM usually fill with rejuvenating activities-quality time for good books, television, movies, concerts, theatre, or just talking on the phone with friends or relatives. Even if we have the time, we may lack the energy to get on the internet to find those who might understand our situation and lend us support. (I, for one, having somehow managed to put dinner on the table, can barely stumble up the stairs and crash until it's time to go to bed for real. Forget about turning on the computer and communicating). Thus, life becomes a sort of subsistence struggle, and that fact, as much if not more than the pain and fatigue caused by FM, leads to depression and more.

I suspect that there are many like myself who can keep up outward appearances, leading the semblance of a normal life and, out of fear of rejection or embarrassment, keep their FM mostly private, carrying it around like a guilty secret, and limiting confidants to some family members and/or a very few close friends.

I would be very grateful if you could share some, or all, of this letter with your readership as long as I could remain anonymous. I would much appreciate reading some reactions to the dilemma described above.

The above letter struck a chord with many of our readers, several of whom sent us letters or emails recounting their own thoughts and experiences. Excerpts of this correspondence, which reflects a number of viewpoints and circumstances, are published below in the hope that they will also have special meaning for you.

☒ I know that many people with FM try to lead "normal lives"--and it literally hurts (to do so); sometimes it feels like there's nobody who could possibly understand just how difficult this attempt is. Sometimes I feel like giving up. Someday, maybe I'll have to give up--I accept that fact. Meanwhile, I'm working full-time at a job where the people wonder from time to time what's wrong with me. I may be stretching at my desk a lot or keeping strange hours to work around my therapy appointments, or I may have a moist-heat wrap around

my neck. I'm also a little unkempt at times...I'm not that "professional looking" since I can't raise my arms above my head to have the right hairstyle every day, and I have to wear cotton since I'm allergic to everything else under the sun. But they tolerate me anyway.

Unfortunately (or fortunately--I'm not sure how I feel about it, yet), I had to "come out" to my supervisor. She saw a book ...on my desk with the word "fibromyalgia" written in giant letters on the cover and asked me why I was reading about it. I'm not quick to lie, so I said it was because "I have it". And she gasped. It seems that she'd just lost an employee to early retirement on disability to FM, and thus her concerns about whether or not I would be able to perform my job suddenly came into question.

☒ Dealing with FM for 47 years has been very difficult, 47 years of looking for pain relief, an end to fatigue, and some level of normal life, hoping each new medicine or therapy will be the answer, only to have my hopes dashed. It is so difficult never being able to plan anything because I never know what tomorrow will bring. I start my days with a prayer that I will be able to cope and try to do the things that have top priority or matter most and still fall short, all the time hating this insidious thing that has robbed me of a good life. Exercise is supposed to be the answer but even starting very gradually makes my condition worse. Most of the medications turn me into a zombie or have other bad side effects. I had to quit my job years ago. I have hobbies that have helped keep me sane through the years, but much of the time I have to use my energy for housework, meals, etc. I'm not able to nurture my friendships. Yet, like the writer [of the "Letter to the Editor"] I'm sure that few would guess my torment (I look good). I put on a happy face to the world and try not to complain too much. Faith and love and understanding from a wonderful husband keep me going.

☒ There are times when I think I can live like this, but there are times when I just can't take another day. It is horrible to be forced to work when you are sick and have been given drugs that affect you in such a way that you can barely keep your eyes open. For many years, I was the sole wage earner, and now I am the larger financial contributor. I am forced to give up everything except work because my medical provider says I am not severe enough for disability, and I cannot afford to work part-time. Because of my lack of energy, life has become a subsistence struggle...People feel that we are habitual complainers and lazy. We know that we aren't. I shared the "Letter to the Editor" with two of my friends. One friend was truly understanding and expressed gratitude for my sharing. The other friend has yet to respond, and two weeks have passed. I guess she doesn't know what to say. I have been suffering for at least 10 years now.

☒ I was very relieved to read the "Letter to the Editor" in the Spring 2000 issue... This is my story EXACTLY. I work full-time and end up hiding my condition from people at work out of fear of "rejection or embarrassment". I, too, have had to give up many of the activities I enjoy because I need to devote more of my energy to work. I have been to two fibromyalgia support group meetings, but I found them discouraging because they were filled with people who have had to stop working. I would love to get a group together for those of us who find ourselves at a different stage. We could share tips, concerns, challenges, etc. How do I find more people like myself? We still suffer but have different issues. Thanks so much for printing the letter ... It is great to know that I am not alone!!

☒ I saw myself in every paragraph [of the "Letter to the Editor"]. I ...have been diagnosed with FM for over seven years. It has waxed and waned, but mostly I've been able to keep working and have what appears to be a fairly normal life. Except, I rarely see friends or attend social functions. Sometimes weeks go by without going to the grocery store. Frequently, my laundry is not done because it involves going up and down a flight of stairs with every load. Why? Because I have a finite amount of energy and must put what energy I have into my job.

As "normal" as I appear, at the beginning of every day I have to think through what I HAVE to do that day. Often that is: Go to work--period. Sometimes I need to stop to pump gas or pick up cleaning or, God forbid,

walk a mall for a belated birthday gift. I calculate the number of times I have to get in and out of the car, the chances of parking close to my destination, and whether or not I can truly withstand the physical demands of the mall. Every day, I ration my energy as carefully as my diabetic father determined the amount of insulin he needed. Usually I reduce the stops or forego shopping because I know if I don't, I will pay a heavy price in pain and energy the next day.

For years, I told no one. Why should others take seriously a malady that I found difficult to even define? Then, several years ago, I decided to be open about my disorder and how it limits my life. The flaw in this ... is that I look normal. I hold down a full-time job. I have children. What my friends and colleagues don't know is that going to work each day is usually all I can do. Frequently, I come home at the end of a workday and go straight to bed. On weekends, rather than maintain friendships or catch up on household demands, I take naps to try to replace the energy I lost during the past week, so I can continue my job the next week.

My house reflects my physical chaos. I have friends who long ago gave up on me and my seeming neglect of relationships. My children alternately understand and feel exasperated with the situation. FM is an eternal frustration. It diminishes me.

☒ The letter to the editor...reminded me of what I was thinking about not too long ago: where do people get all the energy they have to go out in the evening, go to movies, go visiting or to parties or the mall, take part in clubs ... and wash the dishes at night, something I now do once a week (in the dishwasher, not by hand) no matter how many stack up . My life has become quite dreary and lonely because if you do not go out and do things, the world will leave you alone and pass you by. If you don't call people, they forget you.

I...have to work, and sometimes, after a few days of FM time at home, I am even GLAD to go to work. I have taken to checking "chats" on the computer at work before I leave for home...Those chats are a lifeline, and it could be anything, not just FM, it's communication with friends.

I once was "Supermom", but now I'm the old lady who falls asleep any time I sit down in a comfortable chair! I did drive to work for a limited time when I twisted my knee, and I napped in the car for about 10-15 minutes [each day]. It made for a most pleasant working afternoon. Frankly, sometimes I would be happy to hide under my desk and take that nap on the hard floor.

Last November, I thought I would start exercising, hoping to build some energy. I bought a dog for a companion, protection, and "doggercizer". (You can't shove a dog into a closet and ignore it, and they HAVE to be walked.) ... I can now walk a bit more than a mile, but [on] humid/hot days, sometimes I do not have the strength, even if the dog forces me to trudge along...

My doctor is a wonderful man and a great doctor who has spent a lot of time furthering the cause of FM sufferers. But while he is extremely supportive, he cannot help it if he is not God almighty! I guess sometimes we wish and hope our doctors were, and perhaps even throw a tantrum when they are not. They can sympathize and tell us how well we are doing, but after they hand out the pills, that seems to be all they can do.

I really wish I had a life. I feel like Patrick Swayze in the movie, *Ghost*: "I had a life!" he shouted when he found out why he died--but he was murdered and suddenly it was all over...

☒ I am writing to respond to the FM sufferer who is a working stiff. I am in the same boat, my situation being that I am my sole support, and I must work...I had a terrible onslaught of FM/CFIDS in 1989 and was lucky to keep my job. My boss was kind enough to let me come in around 9:30 in the morning, and I left at 5:30, had dinner and rested, and worked some in the evening at home. I didn't know what was wrong, but I

knew I was very sick. After I was diagnosed by chance in 1996, I studied this disease and have made the following accommodations to it:

- ❖ When the overpowering fatigue hits me, I immediately give into it after work for as many days as it takes for the fatigue to lift. I eat out or skip dinner and go to bed at 7 p.m...
- ❖ I have physical therapy (massage, heat, and neurostimulation) every two weeks. This helps my rest at night, my discomfort, and most of all decreases [my] migraine headache incidence...
- ❖ I commuted into Washington, DC, for four and one half years, and that life is a killer for anybody, much less someone with FM. Being single with no one to help with chores or errands, I chose to employ household help instead of being able to take a nice vacation. By now, this biweekly assistance is indispensable. I really could not get along without it.
- ❖ The loneliness and handicapped free time is a problem all right...I've been asked to run some projects for my church and service club and have learned to be wary of saying yes. While the projects may not seem huge to the people asking, I did get in trouble by trying to work them into my life... [The result was] getting a virus and having to miss work...

Like the writer [of the "Letter to the Editor"], no one knows about this problem but my family and very close friends. I have kept it a dark secret at work from the moment it was diagnosed... I've never felt the need to let down my guard on this. I think most people would think me neurotic, lazy, or maybe even mentally ill. Hardly anyone knows anything about this disease, and I think it is self-defeating to discuss it with people who don't have a solid, long-standing relationship with me already.

I could use a buddy to encourage me to pursue those avenues I know are good for me...and to commiserate with when that is the mood I am in. In turn, I could be a source of encouragement and cheer for someone else. I would have joined a support group, but the ones I am near do not meet in the evening; their members don't work.

☒ I, too, have fibromyalgia but don't struggle to the point where I am significantly disabled. I was fortunate enough to be able to stop working when I was diagnosed in 1996, but I am a "full-time mom" with three young children. Even though I don't have a job outside of the home, it takes a tremendous amount of energy to get through the day, and around 4 p.m., I begin to get so tired that I can barely function--probably a lot like others feel when they get home from work...

After my diagnosis, I did not want anyone to feel sorry for me, so I only told a few close friends and family members. My husband and mother were very supportive, but another close family member told me, I must have "bored housewives syndrome". Also, the word got out to some of my old friends whom I had known for years. The word was I was "ill", and the next time I saw the group, I felt like people were pitying me. Only one person had the nerve to bring it up when we were all together, and she treated me like I only had a few days to live!

After that experience, I went into semi-denial. I was going to show the world that I was normal! I didn't tell any of my new friends at church about my fibromyalgia at all. I wanted to be treated like everyone else. All of my new church friends seemed to have picture-perfect, healthy, problem-free lives, and I was going to have people believe, at least, that I did, too! That worked for a while.

Then, last December, I had the worst flare-up I have ever had in my life. I was in such terrible pain that I could no longer function. I couldn't fully take care of my three young children and went into a depression. At that point, I had to stop pretending because I needed other people to help me, physically and mentally.

Thankfully, I feel so much better now, but I learned a lot from that awful experience. It was at that time that I "came out of the fibromyalgia closet", so to speak!...

By being open about my problems to others, they were open with me. My friends told me stories of personal struggles and burdens they have had to deal with. They cooked me dinners; they took care of my kids; I was not alone....How can people be sympathetic if they don't know what FM is? I sure didn't when I was diagnosed.

Also, by being open about my FM, I have met so many others who have it, too. It is unbelievable how many people have fibromyalgia. I live on a small street with only 35 houses, and four women in the neighborhood have FM! I have people from church calling me who have fibromyalgia because they heard I have it. If you feel isolated, you are not alone! Sure, some people still give me a funny look when I say I have fibromyalgia, but I can honestly say that most people have heard of it and have some understanding...

☒ (From the parent of a FM patient) Even if a family member has FM, it seems incredibly presumptuous for anyone on the "outside" of the pain, isolation, and despair of fibromyalgia to take on the task of writing something that will help focus our energies in positive ways. Why is that so difficult? Ecclesiastes says: "time and chance happeneth to all people". Women know all about "time"; who will let us forget it? But "chance" in women's lives often takes the form of a chance remark: "Oh, those support groups reek of tiresome handwringers" or "You don't look sick; maybe you just need some regular exercise". Funny? Devastating? It reminds me of Professor Higgins in *My Fair Lady* who has such confidence that men handle crises with style that he sings: "Why can't a woman be more like a man? Men are so decent, such regular chaps; ready to help you through any mishaps; ready to buck you up whenever you are glum. Why can't a woman be a chum?"

If for once we were to stand on the high ground and take the time to examine how we have been socialized into thinking we must do everything perfectly, at home and on the job, it might help all of us search out new strategies for living in the 21st century. Trying to achieve perfection drains us spiritually, intellectually, and emotionally. We need time to nourish ourselves, not just others. What if we shouldered the pain; moved as we could across restrictive boundaries; created a world where we were free to writhe in pain or sing and shout for joy; love ourselves and each other as we are, not as we are supposed to be? If we really recognize each other, will the world be blown apart?