

LOVE LETTER TO NORMALS

By: Claudia Marek

Here is my letter written to explain to family and friends what it's like to have fibromyalgia. It won't work miracles: it's hard to understand our illness from the outside looking in. But it is a start and can open the door to important dialogues. You are all welcome to use it, either as is, or as a basis for writing your own. Remember that you have a responsibility to tell those close to you what is wrong and communicate as clearly as you can how you feel and what you need. The best time to do that is when you are not upset!

Fibromyalgia isn't all in my head, and it isn't contagious. It doesn't turn into anything serious and nobody ever died from fibromyalgia (thought they might have wished they could on really awful days!!) If you want to read articles or books about fibromyalgia I can show you some that I think are good. If you just want to learn as we go along, that's fine too. This is definitely going to be a process. The first step is for you to believe that there is an illness called fibromyalgia and that I have it. This may sound simple, but when you hear about my symptoms I don't want you to think I'm making this all up as I go along.

Fibromyalgia is a high maintenance condition with lots and lots of different kinds of symptoms. There's no way to just take a pill to make it go away, even for a little while. Sometimes a certain medication can make some of my symptoms more bearable. That's about the best I can hope for. Other times I may take a lot of medication and still won't feel any better. That's just the way it goes. I can't control how often I feel good or when I'm going to feel terrible. Lots of people have been cutting new drugs advertisements out of magazines for me and I appreciate the thought, but I've seen them too. Look at the list of side effects and the few symptoms they help in return. Even in the best studies those expensive compounds didn't help over half the people who tried them. No matter how happy the people in the pictures look, there's still no miracle drug available.

There's no cure for fibromyalgia and it won't go away. If I am functioning normally, I am having a good day. This doesn't mean I'm getting better -- I suffer from chronic pain and fatigue for which there is no cure. I can have good days, several good weeks or even months. But a good morning can suddenly turn into a terrible afternoon. I get a feeling like someone has pulled out a plug and all my energy has just run out of my body. I might get more irritable before these flares, and suddenly get more sensitive to noise or just collapse from deadening fatigue. Weather changes can have a big effect on how I feel. Other times there may be no warning, I may just suddenly feel awful. I can't warn you when this is likely to happen because there isn't any way for me to know. Sometimes this is a real spoiler and I'm sorry. The sadness I feel for what my illness does to those around me is more than I can easily describe. You may remember me as a light-hearted fun loving person -- and it hurts me that I am no longer what I was.

Fibromyalgics have a different kind of pain that is hard to treat. It is not caused by inflammation like an injury. It is not a constant ache in one place like a broken bone. It moves around my body daily and hourly and changes in severity and type. Sometimes it is dull and sometimes it is cramping or prickly. Sometimes it's jabbing and excruciating. If Eskimos have a hundred words for snow, fibromyalgics should have a hundred words for pain. Sometimes I just hurt all over like I've been beaten up or run over by a truck. Sometimes I feel too tired to lift up my arm.

Besides pain, I have muscle stiffness which is worse in the morning and evenings. Sometimes when I get up out of a chair I feel like I am ninety years old. I may have to ask you to help me up. I'm creaky and I'm klutzy. I trip over things no one can see, and I bump into the person I am walking with and I drop things and spill things because my fingers are stiff and my coordination is off. I just don't seem to connect the way I should. Hand-eye, foot-eye coordination, it's all off. I walk slowly up and down stairs because I'm stiff and I'm afraid I might fall. When there's no railing to hold on to, it's terrifying.

Because I feel bad most of the time, I am always pushing myself, and sometimes I just push myself too hard. When I do this, I pay the price. Sometimes I can summon the strength to do something special but I will usually have to rest for a few days afterwards because my body can only make so much energy. I pay a big price for overdoing it, but sometimes I have to. I know it's hard for you to understand why I can do one thing and not another. It's important for you to believe me, and trust me about this. My limitations, like my pain and my other symptoms are invisible, but they are real.

Another symptom I have is problems with memory and concentration which is called fibrofog. Short-term memory is the worst! I am constantly looking for things. I have no idea where I put down my purse, and I walk into rooms and have no idea why. Casualties are my keys which are always lost, my list of errands, which I write up and leave on the counter when I go out. Even if I put notes around to remind myself of important things, I'm still liable to forget them. Don't worry, this is normal for fibromyalgics. Most of us are frightened that we are getting Alzheimer's. New kinds of brain scans have actually documented differences in our brains.

I mentioned my sensitivities earlier and I need to talk about them again. It's more like an intolerance to everything. Noise, especially certain noises like the television or shrill noises can make me jittery and anxious. Smells like fish or some chemicals, or fragrances or perfume can give me headaches and nausea. I also have a problem with heat and cold. It sounds like I'm never happy but that isn't it. These things make me physically ill. They stress me out and make my pain worse and I get exhausted. Sometimes I just need to get away from something, I just don't know how else to say it. I know sometimes this means I will have to go outside, or out to the car, or go home to sit alone and that's really all right. I don't want or need you to give up doing what's important to you. That would only make me feel worse. Sometimes when I feel lousy I just want to be by myself. When I'm like this there's nothing you can do to make me feel better, so it's just better to let me be.

I have problems sleeping. Sometimes I get really restless and wake up and can't get back to sleep. Other times I fall into bed and sleep for fourteen hours and still be tired. Some nights I'll toss and turn and not be able to sleep at all. Every little thing will keep me awake. I'm sure that's confusing to be around, and I know there are times when my tossing and turning and getting up and down to go to the bathroom disturbs you. We can talk about solutions to this.

All these symptoms and the chemical changes in my brain from pain and fatigue can make me depressed as you'd imagine. I get angry and frustrated and I have mood swings. Sometimes I know I'm being unreasonable but I can't admit it. Sometimes I just want to pull the covers over my head and stay in bed. These emotions are all very strong and powerful. I know this is a very hard thing about being with me. Every time you put up with me when I'm in one of my moods, secretly I'm grateful. I can't always admit it at the time, but I'm admitting it now. One thing I can tell you is it won't help to tell me I'm irrational. I know I am, but I can't help it when it's happening.

I have other symptoms like irritable bowel, muscle spasms and pelvic pain that will take their toll on our intimacies. Some of these symptoms are embarrassing and hard to talk about but I promise to try. I hope that you will have the patience to see me through these things. It's very hard for me too because I love you and I want to be with you, and it makes everything worse when you are upset and tired of dealing with all my problems. I have made a promise to myself and now I am making it to you: I will set aside time for us to be close. During that time we will not talk about my illness. We both need time to get away from its demands. Though I may not always show it I love you a million times more for standing by me. Having to slow down physically and having to get rid of unnecessary stresses will make our relationship stronger.



THIS LETTER IS REPRODUCED FROM MY BOOK: FIBROMYALGIA: THE FIRST YEAR. IT'S AVAILABLE FROM BOOKSTORES AND HERE ON THE WEBSITE WHERE ALL SALES BENEFIT THE TREATMENT CENTER. CLICK ON THE BOOK TO ORDER