A Fibromyalgia Letter to Friends and Family

by STARLA RICH

What You Need to Know About Fibromyalgia And Relationships

A wise person once stated, “no man is an island.” No matter how strong or independent we desire to be as individuals, the truth is we all need each other, and we are much stronger with others than we are on our own.

Those with debilitating health issues such as is suffered by patients diagnosed with fibromyalgia, know the struggle in maintaining balance and nurturing the various relationships in their lives. Because pain and fatigue are chronic, and emotional swings and bouts of depression are a reality, it becomes easier to simply isolate rather than try and explain what we are going through.

Also, a sense of frustration and guilt over not being “our best” causes us to shy away from asking for help or support. If a fibro sufferer is not careful, we can find ourselves sinking into a dark hole of isolation.

Below is a letter that I have drafted for those I love. Perhaps it can be a guide for you as well to bring understanding and to better provide them the place in your life that many of them want, and that you desire and need.

A Fibromyalgia Letter to Friends and Family

Dear Family and Friends,

I don’t recall the first day things began to change. Looking back, I wonder if I have not suffered this horrible illness my whole life. Those of you who have been around for any length of time, remember some of my struggles with chronic fatigue, digestive and stomach issues, migraines, and more throughout my life.

Looking back, I so wish someone had known about fibromyalgia way back when. How different the journey might’ve been – not just for me, but for all of you who have lovingly walked every step of the way with me!

Thankfully though, I eventually received a diagnosis that allowed me to put a name and a face to the “monster” that haunted me all these years. Taking it out of the shadows did so much for me, personally, to diminish how large it seemed for so, so long.

What Does Fibromyalgia Feel Like?

Early on, I remember days when it hurt even to blow dry my hair. Chronic migraines were only exasperated that excruciating pain. Can you believe that “air” could hurt that much?

I’ve tried to explain what my body feels, but I am sure I had fallen short when you asked about my pain. The only comparison that I could think of was this. The nerve sensitivity and pain are like an electrical cord that has been stripped of the protective coating, and I am feeling the shocking sensation throughout my body.

The sensitivity to touch is like a bear is squeezing me rather than gently hugged by one of you. Please don't feel that you can't touch me though. I need it more than you could know. Gentle touch, hugs, lightly massaging my head or shoulders is like medicine and therapy to me. Be patient, please. I know I might cry or wince or pull back, but I need you! If it is too much some days – I am sorry, but don't give up.

When my condition was in full flare-up in the beginning, it was like laying down on a bed of nails each evening when I tried to sleep. I had to bury myself in pillows – between my ankles, my knees, under my hands and arms, behind my back, tucked under my neck and shoulders. So much for rest on these awful nights of tortured sleep – if you can even say I slept.

Fibromyalgia and Intimacy

Intimacy? Well, all those pillows were not a wall I assure you! The irony is that just like I mentioned the healing power of hugs and touch by all of you, the power of intimacy from a spouse brings relief as well.

I tried to convey that the best I could as a wife. I found so much relief from my headaches and body aches through loving moments and despite what you fear most, I won't break! Endorphins are better than a shot, and with the reduction of pain and stress, restful sleep is more attainable.

Next page: understanding the physical and emotional impacts of fibromyalgia, the importance of loving someone with fibromyalgia and more.

A Fibromyalgia Letter to Friends and Family, Cont.

The Physical and Emotional Impacts of Fibromyalgia

I have learned much over the years about diet, personal habits, environment, and various things that can assist in better sleep, but I still have fitful, restless nights sometimes. For reasons that the experts still do not fully understand, it seems that those with fibromyalgia do not reach that deep level of sleep like we should each night even when altering our diet and daily habits.

Our nervous system is in overdrive, our muscles knotted from the pain; rest is sporadic, pain disruptive, and this is the reason that I wake feeling more tired than I did the night before. It's impossible to feel refreshed when your body is not producing the serotonin needed. I am coping much better than I did in the beginning, but I still have these days when getting dressed is the most daunting task of the day.

I am not a morning person and have always been slow – I admit that, but even with that bad habit, please understand that if it takes me three hours to even function at the start of the day, it isn't because I am lazy or procrastinating or dragging.

I Am Trying My Hardest

It just hurts sometimes! Holding a mascara brush steady to apply makeup is painful. Bending and stretching to shower, towel dry, put on shoes, button a shirt, or zip up a blouse becomes a chore on those not so great mornings.

Caring for my family, cooking, and entertaining for friends has always been something I adore and thrive in. I am sure you have noticed that some of the spark and energy that has always been there, wanes at times.

I've cried a lot of tears over that and have felt guilty when I just couldn't get moving to have dinner ready on time. Most of you know I am a bit of a perfectionist and OCD when it comes to things around the house.

If I am overly dramatic over the fact that I've left a sink full of dirty dishes or repeatedly apologize because there are no clean towels or work clothes, you know how I am. I don't like leaving things undone, disorderly.

This is a new way of going through my day – letting go and living without everything being at a certain standard. Some days I can run circles around everyone, but other days it looks like a tornado has hit the house and I got caught up in the whirlwind – disheveled and unkept.

You've Helped Me and My Self-Esteem

Goodness I used to be a bit vain in my appearance, didn't I? Well, I suppose I still am, but on those brutal fibromyalgia flare-up days, I am doing good just to get dressed.

Thank you for making me feel loved and seeing my "true beauty." You will never know how much your encouragement means to me.

Chronic pain and fatigue have a way of whittling down your self-esteem and taking you to a depressive state you never thought you'd be in. I know. I am such an optimistic person – always have been.

I guess it does seem like a stranger has invaded my body and soul at times doesn't it when I am frustrated, angry, a bit short tempered and distracted? Those times are what the professionals call "fibro fog" moments.

I have always had such an excellent memory, so it is quite disconcerting for me, as I see it has been for you when I forget things. Thank you for caring enough to jog my memory, remind me of calendar events, repeat things when I ask.

Lastly, Understanding The Importance of Loving Someone With Fibromyalgia

Mostly, I suppose I am learning how to ask for help. Everyone knows how independent I am!

If I ask you to run by the store on the way home because I am not up to buying groceries or need help cleaning up the kitchen, putting away clothes or even cooking a meal, I might not be as straightforward as I should be and sometimes it might inconvenience you just a bit.

Thank you for reading between the lines what I need and thank you for loving me enough to fill in the gap on my not so good days. It has taken me a long time to realize that the total of who I am is not defined by all the things I can do for others, but by the love I have for each of you. You are my heart!

Lastly, I need you to know that I am giving it my best to maintain control of this awful condition. Fibromyalgia was a gamechanger not just for me but for each of you. You didn't ask for your daughter, mother, companion, friend, employee, team member and neighbor to be weakened in her roles of life.

You've stepped up and encouraged me and challenged me when needed, and you've pampered me and showered me with love and TLC.

You've even fought for me and defended me with those who do not understand the devastation this illness brings. So many people think because I look healthy and energetic that I am not suffering.

Fibromyalgia is one of those illnesses that people don't always see, but it is nonetheless real and debilitating. You, my sweet family and friends - my "tribe" are my heroes! I want to have the courage to be yours as well.

All my love,

Starla