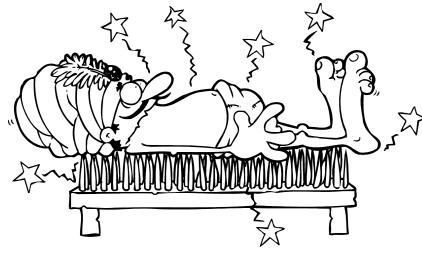


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Marge Cheston ... **On Adjusting**

When I was finally diagnosed with fibromyalgia syndrome (FMS), I was amazed that there was actually a name to cover all those weird and widespread body happenings that I was experiencing. I remember being truly blown away when I learned that other people had it too. I thought, "Wow, I am not crazy, I am not the only one". I am not the hypochondriac, sicko, put-on that some people thought me to be. I am not what various physicians, friends, family members, co-workers and, even I, sometimes thought or said.

If you have fibromyalgia, by now you know that along with your diagnosis comes change. Because you have something that other people cannot see, you automatically become a full-fledged member of the "Invisible Chronic Illness Club". This is a club whose members do not want to belong. Initiation rites include pain (lots of pain), doubt, disbelief, shock, and even denial (NOT ME!). But at least you now have a name to attach to all the odd things your body has decided to do without your permission. You have fibromyalgia, a really big word, a mouthful as well it needs to be for all it entails.

Now that I knew the name of what I had, I decided I needed to educate myself about it. When people said, "What is that?" (FMS), I knew I should be able to say more than "a pain". I needed to understand FMS for myself. So, I set about making it a priority. In those "Old Days" there wasn't much information readily available to us which meant investing a lot of time and effort in gathering knowledge. As I started, I learned new words such as Substance P, serotonin, allodynia, myofascial, as well as the "mere" fact that I had tender points. Later came strange new expressions like "Fibro-Fog", "Brain Fog" and even "Cerebral Flatulence", whatever that means! I also acquired new meanings to familiar words like pain, sleeplessness, energy level, and as time went by I even learned what NO really means. New words, new meanings to old words.

This all seemed to point to another word: ADJUST. In case you didn't know, the word fibromyalgia really means adjust. I now must adjust my thinking, my lifestyle, and even my attitude. That's a lot of adjusting for one person to handle. That's when I realized uh oh, it wasn't just ME who had to adjust. There were also others, too, and that was the really hard part.

I now reasonably understood that fibromyalgia accounted for my constant pain, my irritable bowel and bladder, my allergy problems, and also for my lack of endurance and non-sleep routine. I knew I had memory blanks, word mix-ups, and the basic "irritable everything." At this point I had a name for it, I had a personal, workable understanding of it, and I knew I had to make a lot of adjustments. Next I was faced with Mission Impossible, trying to get others to catch up with me.

Lest you start out thinking, "I can do this", I am here to tell you, "Not so fast; this is not easy". The realization soon dawns that unless you have FMS, you cannot fully understand it, no matter how hard you try. So you settle for getting through just a little bit to anyone who is willing to listen, believe, or try to

understand you. Some can accept and adjust; some cannot or will not. It has to be a very difficult thing for others to do. Look how hard it is for us when we really know how we feel and think.

If you can find even one person who also has FMS, it can be a life ring in a stormy sea. Someone who says "Yes, I understand and know just what you are talking about" and you know they really do. I personally think the name of another FMS sufferer should be a prescription given with the diagnosis.

As part of my "adjustment mode" I find humor a necessity. Believe it or not, there really is some still there, and some days I find it to be my salvation. I have a mental cartoon picture of myself in the morning as I lie in bed kicking the covers around and pulling and grabbing at them. That's enough to make anyone laugh. Actually, I manage to get some gentle exercise, and as a bonus when I get up the covers are pretty well straightened and the bed is a lot easier to make!

I also have to really laugh at the cartoon image of me on a really bad FMS day when I need to sit on the toilet seat after showering and use my hair dryer to dry off my feet and legs. Funny for sure, but it works!

Adjustment can even be good. I decided to sit in each room of my home and look to see which items were causing me pain. This helped me to simplify life by getting rid of some things, making necessary changes, and packing away some of the dust catchers. Try to eliminate as many high maintenance items as possible. Out of sight, out of mind.

In the kitchen I was able to make a small sit-down work area and traded my heavy stoneware dishes for my daughter's lightweight CorrelleT dinnerware. I bought some large handle utility pieces and some fat wooden handled silverware. I put thick carpeting pads where I tend to stand the most, with the most-used items at easy-to-reach levels. It makes for a weird kitchen, but the benefits are great. I even had an 18" block made to set my clothes dryer on so I can load and unload without bending.

For those of us who are overachievers, it is important to find ways to function without creating more pain for ourselves. We are independent by nature, and it is hard to ask others for help. Realizing you can't do it all may take some time. It is not an abuse to ask another for assistance. It's just another adjustment.

While I am adjusting to my "new life", my husband is adjusting to his "new wife". Mind you, I didn't say new and improved, as they like to say in the TV commercials. He is now adjusting to things like the moaning sounds of ooohhh and ahhhh that I make when he rubs my back and neck or the way a light hug can be met with a scream loud enough to pop an eardrum. It is confusing for him when I say I hurt too badly to do anything without even a band-aid to show for it. It also takes a lot of control on his part not to laugh when early morning produces a wife who walks like a penguin then gets to the kitchen and can't find the coffee pot and complains that the toaster isn't working only to be shown it plainly isn't plugged in.

What does one say to a wife who says Alice told her something or other today and leaves it up to her husband to figure out if Alice is someone he knows (although there may be a name mix-up) or one of those faceless people that his wife talks to on the fibromyalgia email hot lines. The big questions for him are "do I ask?" and "is it worth it"?

With a wife who is no longer employed, there is no news about co-workers. They are gone as are many old friends who have fallen by the wayside. Computers bring many "invisible" friends and lots of email. It can be unnerving to know your once "normal" wife now mostly has friends she wouldn't recognize if she passed them on the street. Yet even more scary is the fact that they totally understand each other. They have a secret language that consists of initials: FMS, MPS, IBS, TMJ, BTW, and LOL.

This new wife says the idea of a vacation makes her cringe. This strange woman who used to have a purse you could live out of now goes shopping with a little 4" x 5" thing with a cord on it. She says it contains all she needs to shop: money, credit cards, a few checks, mini-pen, her I.D., and a pain pill to make shopping possible.

Now as a pair these two people are thinking of defining FMS. He is thinking "Frustrated Male Saga", and she "Forget My Security". Thus a trip to the Doubleday dictionary to define "Adjust": Change to make fit, put in proper order, position or relation, arrange. Accommodate oneself. Yep, that sounds like home to me.

As a person with fibromyalgia, I have learned the rules of "play and pay". We have to weigh those chores, trips, and tasks at hand with "is it worth the pain I will pay with if I do it?". Sometimes it is yes, and at times it is no. I can say to you that when you are ready to accept your new lifestyle, you will have reached the point where you have grieved for your old life and then put it away. After that, some of the ruts will smooth out. Just remember very few people, if any, have a perfect lifestyle. Some are better than ours, and there are still those a lot worse. Hey, we are alive, we are not deformed, and we still have choices.

If you have a phone, a computer, or even a pencil and paper, you don't need to be alone. You need and can have a friend, hopefully a "FMS Buddy"--one who can understand and accept you for what you are today. Social isolation is your worst enemy. Don't do it.

Like you, I still don't know why we have this. I don't pretend to have the answers or imply life is great. I only say to you as an FMS Friend that the more you adjust, the easier it will become for you. Even with all of the information available today, the bottom line still is that they don't know why we have it; they haven't found a cure for it; not one treatment fits all; and there is no magic pill.

While we all wait for the answers, remember to be kind to yourself. You are the only one who truly knows how you feel. Change what you can and adjust, adjust, adjust. Find some humor and above all know for sure that fibromyalgia is not forcing only you to adjust. Medical, pharmaceutical, research, therapy, insurance, government and even local and worldwide communities are having to find the time, information, resources and money to adjust to fibromyalgia. This "invisible, chronic illness" we have at least now has an accepted, recognizable name, and we can no longer be told it is in our heads and not our bodies.

Remember, a little adjustment goes a long way with FMS!