

"Letter To "Normals"

Having FMS/MPS means many things change, and a lot of them are invisible. Unlike having cancer or being hurt in an accident, most people do not understand even a little about FMS/MSP and its effects, and of those that think they know, many are actually misinformed.

In the spirit of informing those who wish to understand.....These are the things that I would like you to understand about me before you judge me....

- Please understand that being sick doesn't mean I'm not still a human being. I have to spend most of my day in considerable pain and exhaustion, and if you visit I probably don't seem like much fun to be with, but I'm still me stuck inside this body. I still worry about school, and work and my family and friends, and most of the time I'd still like to hear you talk about yours too.

-Please understand the difference between "happy" and "healthy". When you've got the flu you probably feel miserable with it, but I've been sick for years. I can't be miserable all the time; in fact I work hard at not being miserable. So if you're talking to me and I sound happy, it means I'm happy. That's all. It doesn't mean that I'm not in a lot of pain, or extremely tired, or that I'm getting better, or any of those things. Please, don't say, "Oh, your sounding better!" I am not sounding better, I am sounding happy. If you want to comment on that, you're welcome. Please understand that being able to stand for ten minutes doesn't necessarily mean that I can stand up for twenty minutes, or an hour. And, just because I manage to stand up for thirty minutes yesterday doesn't mean that I can do the same today. With a lot of disease you're either paralysed, or you can move. With this one it gets more confusing.

-Please repeat the above paragraph substituting "sitting", "walking", "thinking", "being sociable" and so on.... it applies to everything. That's what FMS/MPS does to you.

-Please understand that FMS/MPS is variable. It's quite possible (for me, its common) that one day I am able to walk to the park and back, while the next day I'll have trouble getting to the kitchen. Please don't attack me when I'm ill by saying "But you did it before!" if you want me to do something then ask if I can. In a similar vein, I may need to cancel an invitation at the last minute, if this happens please do not take it personally.

-Please understand that "getting out and doing things" does not make me feel better, and can often make me seriously worse. Telling me I need a treadmill, or that I just need to loose (or gain) weight, get this exercise machine, join this gym, try these classes... may frustrate me to tears, and is not correct....if I was capable of doing these things , don't you know that I would? I am working with my doctor and physical therapist and am already doing the exercise and diet that I am suppose to do. Another statement that hurts is, "You just need to push yourself more, exercise harder..." Obviously FMS/MPS deals directly with muscles, and because our muscles don't repair themselves the way your muscles do this does far more damage than good and could result in recovery time in days or weeks or months from a single activity. Also, FMS/MPS may cause secondary depression (wouldn't you get depressed if you were hurting and exhausted for years on end?) but it is not created by depression.

-Please understand that if I say I have to sit down/lie down/take these pills now, that I do have to do it right now...it cant be put off or forgotten just because I'm out for the day (or whatever). FMS/MPS does not forgive.

-If you want to suggest a cure to me, don't. It's not because I don't appreciate the thought, and it's not because I don't want to get well. It's because I have had almost every single one of my friends suggest one at one point or another. At first I tried them all, but then I realized that I was using up so much energy trying things that I was making myself sicker, not better. If there were something that cured, or even helped, all people with FMS/MPS then we'd know about it. This is not a drug company conspiracy, there is worldwide networking (both on and off the Internet) between people with FMS/MPS, if something worked we would know.

-If after reading that, you still want to suggest a cure, then do it, but don't expect me to rush out and try it. I'll take what you said and discuss it with my doctor.

In many ways I depend on you....people who are not sick....I need you to visit me when I am too sick to go out....Sometimes I need you to help me with the shopping, cooking or cleaning.

I may need you to take me to the doctor, or the physical therapist. I need you on different levels...you're my link to the outside world...if you don't come to visit me then I might not get to you.

...and, as much as it's possible, I need you to understand me.

Source: www.fibrohugs.com