

Letter to Normals: Getting Others to See Your Symptoms

by Ricky Buchanan *



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 flat on my back in bed and I might not seem like great company, 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. I may be tired. I may be in pain. I may be sicker than ever. Please, don't say, "Oh, you're 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 up for five minutes, doesn't necessarily mean that I can stand up for ten minutes, or an hour. It's quite likely that doing that five minutes has exhausted my resources and I'll need to recover – imagine an athlete after a race. They couldn't repeat that feat right away either. With a lot of diseases you're either paralyzed or you can move. With this one it gets more confusing.

Please repeat the above paragraph substituting, "sitting up", "walking", "thinking", "being sociable" and so on ... it applies to everything. That's what a fatigue-based illness does to you.

Please understand that chronic illnesses are variable. It's quite possible (for me, it's 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, ask if I can and I’ll tell you. In a similar vein, I may need to cancel an invitation at the last minute, if this happens please don’t take it personally.

Please understand that “getting out and doing things” does not make me feel better, and can often make me seriously worse. Fibromyalgia may cause secondary depression (wouldn’t you get depressed if you were stuck in bed for years on end!?) but it is not caused by depression. Telling me that I need some fresh air and exercise is not appreciated and not correct – if I could do it, I would.

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 can’t be put off or forgotten just because I’m doing something. Fibromyalgia does not forgive.

Please understand that I can’t spend all of my energy trying to get well. With a short-term illness like the flu, you can afford to put life on hold for a week or two while you get well. But part of having a chronic illness is coming to the realization that you have to spend some energy on having a life now. This doesn’t mean I’m not trying to get better. It doesn’t mean I’ve given up. It’s just how life is when you’re dealing with a chronic illness.

If you want to suggest a cure to me, please 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 was something that cured, or even helped, all people with Fibro 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 Fibro, if something worked we would KNOW.

If after reading that, you still want to suggest a cure, then do it, preferably in writing, but don’t expect me to rush out and try it. If I haven’t had it suggested before, I’ll take what you said and discuss it with my doctor.

Please understand that getting better from an illness like this can be very slow. People with Fibro have so many systems in their bodies out of equilibrium, and functioning wrongly, that it may take a long time to sort everything out.

I depend on you – people who are not sick – for many things.

But most importantly, I need you to understand me.

*A “Letter to Normals” by Ricky Buchanan originally appeared online in 1995 at <http://notdoneliving.net>. Since then, she has been happy to share this worldwide. We wanted to share it with all of you