



UK Lichen Planus

Chronic Pain

Having chronic pain 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 chronic pain 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 or call me on the 'phone sometimes I probably don't seem like much fun. But I'm still me -- stuck inside a body which doesn't work as it should.

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 nearly ___ years now. 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, you're sounding better!" or "But you look so healthy! **I am merely coping.** I am sounding happy and trying to look normal.

Please understand that being able to stand up/sit down/walk for ten minutes doesn't necessarily mean that I can stand up/sit down/walk for twenty minutes, or an hour. Just because I managed to stand up/sit down/walk for thirty minutes yesterday doesn't mean that I can do the same today. With a lot of diseases you're either paralyzed, or you can move. With this one, it gets more confusing everyday. It can be like a yo-yo. I never know from day to day, how I am going to feel when I wake up. **In most cases, I never know from minute to minute.** That is one of the hardest and most frustrating components of chronic pain.

The above paragraph could be repeated with; thinking, concentrating, being sociable and so on - it applies to everything - that's what chronic pain does for you.

Please understand that chronic pain is variable. It's quite possible (for many, 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 next room. Please don't attack me when I'm ill by saying or even thinking; "But you did it before!" or Oh, come on, I know you can do this! If you want me to do something, then ask if I



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can. In a similar vein, I may need to cancel a previous commitment at the last minute. **If this happens, please do not take it personally.** If you are able, please try to always remember how very lucky you are--to be physically able to do all of the things that you can do.

Please understand that "getting out and doing things" does not make me feel better, and can often make me a lot worse. You don't know what I go through or how I suffer in my own private time. Telling me that I need to exercise, or do some things to get my mind off of it may frustrate me to tears, and is not correct - if I was capable of doing some things, any or all of the time, don't you know that I would? I am working with my doctor and I am doing everything I can to manage the situation.

Another statement that hurts is, "You just need to push yourself more, try harder..." Obviously, chronic pain can deal with the whole body, or as in my case be localized to specific areas. Sometimes participating in a single activity for a short or a long period of time can cause more damage and physical pain than you could ever imagine. Not to mention the recovery time, **which can be intense and long.** You can't always read it on my face or in my body language. Also, chronic pain may cause secondary depression (wouldn't you get depressed and down if you were hurting constantly for months or years?), but it is not created by depression.

Please understand that if I say I have to stand up/sit down/lie down/stay in bed/or take these pills now, that probably means that I do have to do it right now - it can't be put off or forgotten just because I'm somewhere, or am right in the middle of doing something. Chronic pain does not forgive, nor does it wait for anyone.

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. Lord knows that isn't true. In all likelihood, if you've heard of it or tried it - then so have I! In some cases, I have been made sicker, not better. This can involve side effects or allergic reactions. It also includes failure, which in and of itself can make me feel even lower.

If there were something that cured, or even helped people with my form of chronic pain, then we'd know about it. There is worldwide networking (both on and off the Internet) between people with chronic pain. If something worked, we would **KNOW.** It's definitely not for lack of trying.

If I seem touchy, it's probably because I am. It's not how I try to be. As a matter of fact, I try very hard to be normal. I hope you will try to understand. I have been, and am still, going through a lot. Chronic pain is



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hard for you to understand unless you have had it. It wreaks havoc on the body and the mind. It is exhausting and exasperating.

Almost all the time, I know that I am doing my best to cope with this, and live my life to the best of my ability. I ask you to bear with me, and accept me as I am. I know that you cannot literally understand my situation unless you have been in my shoes, but as much as is possible, I am asking you to try to understand in general.

In many ways I depend on you - people who are not sick. I need you to visit me when I am too sick to travel ... You are my link to the normalcy of life. You can help me to keep in touch with the parts of life that I miss although I fully intend to undertake them again, just as soon as I am able.

Thank you for listening. It really does mean a lot.