



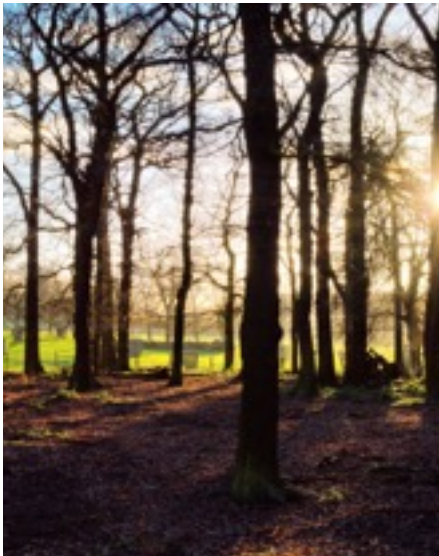
A Letter to People without Chronic Pain

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, sometimes 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, my family, my friends, and most of the time – I'd still like to hear you talk about yours, too.



Tim Hill
t-hill.com

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, you're sounding better!” or “But you look so healthy!” I am merely coping. I am sounding happy and trying to look normal. If you want to comment on that, you're welcome.

Please understand that being able to stand up for ten minutes doesn't necessarily mean that I can stand up for twenty minutes, or an hour. Just because I managed to stand up 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.

Please repeat the above paragraph substituting, “sitting”, “walking”, “thinking”, “concentrating”, “being sociable” and so on ... it applies to everything. That's what chronic pain does to 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, "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 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.



dazmac
@madonions

Please understand that "getting out and doing things" does not make me feel better, and can often make me seriously 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 what I am supposed to do. Another statement that hurts is, "You just need to push yourself more, try harder..." Obviously, chronic pain can deal with the whole body, or 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. 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 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, 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, after reading this, you still feel the need to suggest a cure, then so be it. I may take what you said and discuss it with my doctor.

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 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 be understanding 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 go out... Sometimes I need you help me with the shopping, cooking or cleaning. I may need you to take me to the doctor, or to the store. 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 and fully intend to undertake again, just as soon as I am able.

I know that I have asked a lot from you, and I do thank you for listening. It really does mean a lot.



by Ned Horton
hortongroup.com

TIPS FOR DEALING WITH PEOPLE IN PAIN



1. People with chronic pain seem unreliable (we can't count on ourselves). When feeling better we promise things (and mean it); when in serious pain, we may not even show up.
2. An action or situation may result in pain several hours later, or even the next day. Delayed pain is confusing to people who have never experienced it.
3. Pain can inhibit listening and other communication skills. It's like having someone shouting at you, or trying to talk with a fire alarm going off in the room. The effect of pain on the mind can seem like attention deficit disorder. So you may have to repeat a request, or write things down for a person with chronic pain. Don't take it personally, or think that they are stupid.
4. The senses can overload while in pain. For example, noises that wouldn't normally bother you, seem too much.
5. Patience may seem short. We can't wait in a long line; can't wait for a long drawn out conversation.
6. Don't always ask "how are you" unless you are genuinely prepared to listen it just points attention inward.

7. Pain can sometimes trigger psychological disabilities (usually very temporary). When in pain, a small task, like hanging out the laundry, can seem like a huge wall, too high to climb over. An hour later the same job may be quite OK. It is sane to be depressed occasionally when you hurt.



8. Pain can come on fairly quickly and unexpectedly. Pain sometimes abates after a short rest. Chronic pain people appear to arrive and fade unpredictably to others.

9. Knowing where a refuge is, such as a couch, a bed, or comfortable chair, is as important as knowing where a bathroom is. A visit is much more enjoyable if the chronic pain person knows there is a refuge if needed. A person with chronic pain may not want to go anywhere that has no refuge (e.g.no place to sit or lie down).

10. Small acts of kindness can seem like huge acts of mercy to a person in pain. Your offer of a pillow or a cup of tea can be a really big thing to a person who is feeling temporarily helpless in the face of encroaching pain.

11. Not all pain is easy to locate or describe. Sometimes there is a body-wide feeling of discomfort, with hard to describe pains in the entire back, or in both legs, but not in one particular spot you can point to. Our vocabulary for pain is very limited, compared to the body's ability to feel varieties of discomfort.

12. We may not have a good "reason" for the pain. Medical science is still limited in its understanding of pain. Many people have pain that is not yet classified by doctors as an officially recognized "disease". That does not reduce the pain, - it only reduces our ability to give it a label, and to have you believe us.