

An Open Letter to Those Without an Invisible Disability or Chronic Illness

Having an invisible disability (ID) and/or invisible chronic illness (ICI) means that many things change. Just because you can't see the changes doesn't mean they aren't real.

Most people don't understand much about these disabilities/diseases and their effects, and of those that think they know, many are actually mis-informed. 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 disabled/sick doesn't mean I'm not still a human being. I have to spend most of my day being very careful what I do, and if you visit I might not 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. 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.

Please repeat the above paragraph substituting, "sitting up", "walking", "thinking", "being sociable" and so on ... it applies to everything that I do.

Please understand that the effects of chronic illnesses and many disabilities are variable. It's quite possible (for me, it's common) that one day I am able to walk to the bathroom and back, while the next day I'll have trouble sitting up. Please don't attack me when I'm worse by saying, "But you did it before!". If you want me to do something, ask if I can and I'll tell you.

Similarly, my illness/disability may vary suddenly, meaning 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 worse. Chronic illnesses/disabilities may cause a secondary/reactive depression (wouldn't you get depressed if you were stuck in bed 23 hours a day for years

on end?) but they are not caused by depression. Telling me that I need some fresh air and exercise is not not correct and probably not appreciated – if I could possibly do it that, 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 else more exciting. Illnesses and disabilities do not forgive their victims easily.

Please understand that I can't spend all of my energy trying to get well from my incurable chronic illness/disability. 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 an important part of having a chronic illness or disability is coming to the realization that you have to spend energy on having a life *while you're sick/disabled*. 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/disability.

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 a certain illness or disability 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 similar and different chronic illnesses and disabilities, if something worked we would *know about it*.

If after reading that, you still want to suggest a cure, then do it if you must. Preferably in writing and accompanied by the scientific papers that prove it works. But don't expect me to rush out and try it. I might not even reply. If I haven't had it or something like it suggested before, and it sounds reasonable, I'll probably take what you said and discuss it with my doctor.

Please understand that getting better from an illness can be very slow. And getting better from an invisible disability might not happen at all. People with chronic illnesses have so many systems in their bodies out of equilibrium, and functioning wrongly, that it may take a long time to sort everything out, if it ever happens.

I depend on you – people who are able-bodied – for many things.

But most importantly, I need you to understand me.

From: <http://notdoneliving.net/openletter/id>