

Dear Loved One,

Having Ehlers Danlos Syndrome 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 this disability/disease 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...

I am scared. I don't know what the future holds for me. Will I end up in a wheelchair or will I be one of the lucky ones. If you find me being quiet and reflective, please don't think I am upset with you. I am trying to sort out my fears.

I am angry. EDS has taken so much away from me. I can no longer do many of things I enjoy doing. I sometimes have difficulty just completing simple tasks. If I appear angry please understand it is EDS I am angry with, not you.

Please understand that having EDS doesn't mean I'm not still a human being. I have to spend most of my day being very careful about 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, work and my family and friends etc, and most of the time I'd still like to hear you talk about yours too.

Please don't assume you know what is best for me. EDS has affected my joints and such, not my mind. I am capable of making my own decisions. If I make the wrong decision, it is I who has to deal with the consequences. I still want to be part of the "gang." Please continue to invite me to participate in activities. I'll decide if I am capable of it. You may think you are being considerate by not inviting me to go ice-skating with everyone else, but it hurts when you exclude me. Maybe I can't skate with everyone else but I can bring the hot chocolate and watch.

Please don't tell me you know how I feel. You don't. Don't offer me sympathy; I don't want your pity. But do offer me support and understanding, which I appreciate. I know sometimes I look perfectly healthy, but looks can be deceiving. Please understand that I am dealing with invisible pain and a lot of fatigue. Even on a good day I feel like you do when you have the flu (tired, achy and sore). Please keep that in mind.

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 (EDS is genetic, this means I have had it since birth (even if I was only diagnosed recently, I have been suffering from this since I was born)). 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 don't tell me how "Auntie Mary" cured her joint problems by drinking vinegar or any other supposed remedy. 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. There is NO cure for EDS (and until they find the exact genes causing it and technology and medicine get to a point where something can be done about this, there will be no cure), only some of my symptoms and pain can be treated. If there was something that helped, then myself and other sufferers would know about it (this is part of the reason I am a member of the online communities I am a member of). 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, and if something worked we would know about it. If after reading this, 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.

I want you to know that the pain and instability etc from EDS moves around. 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. Just because I climbed the stairs yesterday (or an hour ago) doesn't mean I can do it today (or in another hour). Yesterday (or earlier) my shoulder was throbbing; today (now) it is my knee, who knows what it will be tomorrow (or later). Also 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 those 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.

Similarly, EDS and the symptoms of it 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. EDS may cause a secondary/reactive depression (wouldn't you get depressed occasionally if you had a body that could change suddenly for no reason, caused you pain 24/7 and could spontaneously rearrange itself through no fault of your own) but they are not caused by depression. Telling me that I need some fresh air and exercise is not correct and probably not appreciated - if I could possibly do it then, 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. EDS does not forgive its victims easily.

Please understand that I can't spend all of my energy trying to get well from EDS it is incurable (and genetic, so unless I can change my genes I cannot change my disease/disorder). 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 like EDS 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 EDS or any chronic illness/disability.

As you can see EDS really Sucks...

Finally, please remember that I am the same person I was before I was diagnosed with (started getting symptoms of) this; EDS doesn't change the heart and soul. I still laugh, I still cry. I still love and I still hate. I am me, I am not my disease. Please continue to love me just as you did before. I need lots of love, understanding, support and hugs, just like you.

But most importantly, I need you to understand me.

Signed

Me (Lynda Ward)

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This is an 'Open Letter' which can be found online. I didn't write it, but it can be shared & put 'out there'. It REALLY does cover what it's like to live with EDS.