

Advice from the Trenches: Chronic

Dear C and Dr. B:

I've just been diagnosed with an autoimmune disorder that I'm going to have forever - IBD (Inflammatory Bowel Disease). Although I supposedly can keep it under control, I have to deal with a lot of discomfort, pain and a need to never be far from a bathroom.

I need to figure out how to live with this! I can't eat like other people. I have to limit certain activities and I sometimes have weird pains that nearly flatten me, then just disappear again. I am not sure what to do when I'm with other people. It scared my boyfriend to death the first time he saw it happen. Yesterday when I talking with a client at work I had a pain so bad I could hardly breathe... Luckily, my supervisor walked in and the customer had a question for him. I covered my reaction, and ducked out.

Should I just let people know this is going on? I can't stand it when people act like babies over aches and pains, but I feel like I'm living a lie if I just pretend nothing is wrong.

- Chronic Connie

Dr. B says:

Honesty is the best policy. Leaving it up to people to misinterpret your painful expressions is a bad idea - it can be misconstrued as disgust or dislike. People often take nonverbal language very personally. They could easily think, "She doesn't like me, she isn't taking me seriously!" As a result, they might complain, or worse, be mean to you. Honesty up front might cause people to be overly sympathetic, which can be annoying, but - so? You will get used to it; that's simply people trying to be nice.

C says:

As a person who has lived with Crohn's Disease, a form of IBD, for over 40 years, my advice is quite the opposite - keep it to yourself, Connie.

A simple question: when people see you coming, do you want them to say "Look, it's Connie, everyone be nice, she has IBD"? Or do you want them to say, "Look, it's Connie. Wow, she killed it at the meeting yesterday!"?

The less attention you pay to pain and discomfort, the less you feel it and this is exactly why sharing your problem with others is so counterproductive - the more you talk about your condition and focus on it, the more real it becomes, until in the end, it is more real than you.

I'm not saying that you should hide real problems, but the only people who need to know your private health concerns are your doctors. If your employer asks about your health as part of employee records, you must, by law, admit that you have an autoimmune disorder but if I were you I would add that you are in remission and under control. Never mention it again.

In all the years that I have been freelancing, I have NEVER told a client I am technically an invalid and

often in pain. It has absolutely nothing to do with my ability to do the job. My clients have learned to trust me. I've never missed a deadline.

If you need support, join a group with people who have the same health problem. They are the only ones who really understand. Healthy people with no experience of chronic illness don't know what to say. They feel obliged to be nice, so they utter vapid condolences or make inane suggestions such as "take a TUMS, that always works for me!" They do this because they have nothing to offer and feel awkward. You are doing them no favor by putting them in that position.

Learning to control your reactions actually has health benefits. When pain twinges are a familiar and recurring thing, it is entirely possible to calm your facial expression and simply wait them out. Such deliberate relaxation also lessens pain; I've been doing this for years. There is no need to create drama or call attention to your symptoms, but if you keep accurate personal records of your episodes you can educate yourself on how your own system works.

Take a lesson from hypnosis - it has been proven to be very effective in helping patients ease pain. But unlike painkillers which mask pain, hypnosis helps you to manage the fear and anxiety you have related to that pain. Anxiety and tension is what increases the existing pain.

Everyone with a chronic condition has two choices: 1) Make your life an endless explanation about your disease and your symptoms until the disease has become your core identity, or 2) Figure out how to deal with your restrictions and symptoms as quietly and efficiently as possible and just live your life.

Research and learn, Connie. You are the best regulator of your own body. If you take really good care of yourself, living a good life with autoimmune disease can be done. I promise.

- Cathren Housley

You can visit Dr. B's blog at drbrilliantcliche.wordpress.com