

## **10 THINGS I Want You to Know About Working** ***While Living with Chronic Illness***

**1. For most people, health, like the weather, is relatively unpredictable and there's an element of luck.** But living with chronic illness means that I face unpredictable health daily. It can change as quickly as the weather, often without warning. I find this difficult, constantly challenging and even demoralizing. But, I try very hard not to let this prevent me from delivering my best.

**2. When I have to "slow down" or not show up because of chronic illness symptoms, it can mean that others have to pick up the pieces to keep things going.** I appreciate that this can be frustrating for you. It is for me, also. Let's just make sure we discuss what I can do to prevent my illness from becoming a burden to anyone.

**3. I'm not looking for your pity or even your sympathy.** I don't feel sorry for myself and I don't want you to feel sorry for me, either. But I do welcome empathy, such as, "I understand this is tough". And once in a while, it's really great to hear your encouragement, such as, "You do a great job with this" (but only if you mean it.)

**4. I know it doesn't seem to make sense, but I can feel terrible and look fine.** When most people have the flu or even just a cold, they look sick. My symptoms, sometimes disabling, are usually invisible. I know it's hard for others to understand this, especially when I look the same through it all. That's why I'm often nervous about what others believe about my health and think about me. It might sound odd but when I hear, "You look so good!" I wonder if you think I'm exaggerating my experience.

**5. You probably think you're being helpful when you tell me what I could do to get better.** Your Aunt Gertrude, who went into remission with that special diet or your friend, Phil, who got better when he stopped working – they're not me. I promise you, if I want advice, I will ask for it. Just because I'm not healthy, it doesn't mean I'm incapable of managing my life.

**6. When I mention my chronic illness, please don't "skip" over it and look away.** When you avoid the subject, it doesn't feel polite or respectful. Instead, it feels as if you're avoiding the topic. The fact is, I appreciate questions that show genuine interest in my experience, such as, "What does this mean for you?" And, I'll try my best to be respectful of you by not overly focusing on the subject.

**7. Have you ever noticed how often people pass you in the office halls with, "How ya' doing?" and they keep walking?** I know it's just a greeting but when I don't feel well, I don't have a quick answer. I'm still responding to the question five minutes later -- in my head. In fact, there are times when it's difficult to carry on simple, normal, office banter when I don't feel "normal" and my life doesn't fit into a sound bite. So if you ask, be prepared for more than you might have bargained.

**8. Healthy people can work (or play) too hard but they can catch up after pushing their bodies too far without too much wear and tear.** Part of the problem with this chronic illness, however, is that my limits can vary greatly. I can't ever be sure how hard I can push without hurting myself. Some days, walking upstairs to the water cooler feels like I'm running the marathon. Sometimes it can take days or even weeks to feel "normal" after working a few late nights and weekends. And, yet, at other times, I can do any of this without a problem. Go figure.

**9. People in the office (particularly management) will tell me, "Take care of yourself, that's most important".** But how should I interpret this message when working 10 hour days/6 days a week is considered a virtue? I want to have high standards for my performance and be respected for what I do, just like everyone else. But, the crazy schedule that we work doesn't allow time for doctors' appointments or time to recoup. I find that there's a bit of a contradiction here.

**10. Please don't assume that because I live with a chronic illness, I can't do my job or take on new responsibilities.** If I say I can do something, I will. I don't want to be protected from work demands and I want to be held to the same high standards as everyone else. I might have to ask for help at times. But, that's my responsibility. Please don't discount me without checking with me first.

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