

Pain - Communication and the Patient Experience

Chronic Pain - Video 2

It's hard to have an illness or a condition that is not visible, because people don't know how to respond to it. They're not expecting it, so I think there's a lot of similarity between chronic pain and mental illnesses like chronic depression or like mood disorders because you don't portray it the way people anticipate and that means you're treated differently or people - you feel people are suspicious that you're just faking it for attention or projecting another image that's not credible. And I think that is definitely hurtful. On the other hand, most people with chronic illness work hard so that that isn't the first thing people see about them. So there's a kind of tug within you like "acknowledge that this is happening to me, and feel a little bad for me"; on the other hand don't describe me like that, don't define me like that; there's way more than just this situation, this day at this time. So it's very complicated. I kind of yearn sometimes that I would have a broken leg and people could say "oh, poor woman, she has a broken leg", and it will get better. As opposed to something that's deep in you, and you're doing your best you can on a daily basis, or a moment to moment basis to grapple with it, or control it or remove it or hide it, but it is very, very difficult sometimes to know what's going on inside, and know what you have to project and what you have to present publicly.

I actually try not to talk about it very much, I really do, and I think if I'm close enough to someone, the signs are often there that I'm holding my head and I'm - I go very pale. And I have very good friends - my family - can tell right away when it's time for another pill. But for the most part I don't want to burden others with it cause there's really nothing they can do. I mean it's not as if I need help crossing a street where there is something someone can do. The kind of kindness that you hope you get from people who care about you should come anyway. But there's a - it's a difficult road because there are the moments that you want to be acknowledged that you're dealing with something big and oppressive and permanent, and that's the notion of 'chronic'. I've always been glad - I think it was Hitchens who said something about it when he was going through his end of life - that you can't really describe pain effectively, and you can't have it described to you. So there's the memory of pain is a vague thing and they always say that about women who have had babies - you can say it really hurt but you can never really actually describe it or remember it because you're holding a baby and that's the good side. So pain is an odd, odd journey, and I think it's an epidemic. I think there are people that deal with pain, you know, your

knees, your back, your elbows - the things that happen with normal aging - and we're hard on our bodies - and then there are the things that are like mine, which came from a stimulus that's inside me. But people are afraid to address their pain and acknowledge their pain. They think it shows a sign of weakness and it shows a sign of compromise, and it's also a denial of everything that's going on inside you. So if you have an illness that a pill will help or medicine will help or treatment will help or an operation will help it's easier because you're going to do what needs to be done, and at the end of the process, no matter how ugly or long it is, you'll be better.

With chronic pain, that's probably not going to happen. And that in itself means, okay, this is my life now, this is who I am, but I don't want everyone to know. I think a lot of well-intentioned people like to talk about it too much, and I think that that's a personality thing. I don't like to talk about it very much, because talking isn't going to change it, and it burdens things, but I do have - have had a number of good friends say, are you getting enough medication, are you getting enough rest, I've tried this, have you tried that, have you seen this specialist, how do you cope, you're doing too much, you should be home resting - and it all means well, it's all meant kindly, but it makes you again feel the burden of your situation as opposed to "I'm dealing with it, and I will deal with, and I'll deal with it with your help as a friend, but not as a clinical guide." And I think that's, you know - that's the other part of it is you have to give someone the space to deal with it in a personal way. And people are different. Some people really get a hangnail and want to talk about it, how it made them feel; and others can have major, major situations in their life that they'd rather step back. But everybody, whether they want to step back or they want to deal with it in a very public way, everyone benefits from the acknowledgement that "I know you're going through something. If there's anything I can do..."