10 Things About People With Fibromyalgia | CPD Blog

Storee Powell

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It started at least 5 years ago with bouts of intense body fatigue and weakness. It continued to progress into bouts of hideous pain. I’d suddenly find myself unable to move after laying on the floor, dropping things constantly, and writhing in pain at night. After a merry-go-round of doctors, misdiagnoses, and awful medications, I finally learned what was eating me alive on July 6, 2016: Fibromyalgia. I’ve learned that most people know little about this chronic illness and invisible disability. The most common response is something along the lines of a nebulous idea of being tired. Here are 10 things to know about people with Fibromyalgia to help you support those around with this disease:

1. The thing about Fibro (as I so refer to it) is that it is all encompassing. It causes sleep disturbances, muscle pain and weakness, joint stiffness, hyperhidrosis, irritable bowel syndrome, headaches, numbness and tingling, tinnitus, environmental sensitivity, balance and dizziness problems, TMJ, anxiety or panic disorders, brain fog, and I’ll stop here before I bore you. Just know that it affects many systems in the body.

2. It isn’t killing us, but it sure feels like it. Though Fibro isn’t terminal, I regularly have such a high pain and fatigue level that I cannot perform basic daily tasks to take care of myself. My least favorite is not brushing my teeth for two days. Angora sweater is the description that comes to mind….

3. Fibro is difficult at best to treat (still no cure). Traditional pain medications do little or nothing to help with symptoms, and only three medications are currently approved for Fibro.

4. We usually don’t ‘look sick’. It is hard to ask for help when you are 29 and know people will question how sick you really are. When you see me, there is a good chance I’m wearing 10 layers of concealer, and it is the first time in a week I’ve left the house.

5. Ninety percent of sufferers are women, and it often starts in the 20’s or 30’s, and takes an average of 5 years to diagnose.

6. It is a grab bag. Every day with Fibro is different – I never know which combination of symptoms I’m going to encounter. Some days I’m semi-functional and some days I am not functional at all. And I can’t predict it. Last minute cancellations are something I dread intensely, and I have severe anxiety about making appointments.

7. I am slow. I’ve had to learn to live life at a different pace than that of a person my age who is healthy. I cannot work the same hours, drive the same distances, do the same physical tasks for longs periods of time, or socialize when I please. Everything I do is very calculated.

8. I won’t ‘get better’. Fibro is chronic – meaning it is for life for the majority of people who have it. Just because you see me looking relatively human one day does not mean I am better. In fact, I’m probably working through a variety symptoms and I’m just good at hiding it.

9. I can’t ‘fight it’. Fibro isn’t cancer. I can’t win (i.e. make it go away with treatments). And honestly, I work three times as hard a healthy person to do basic things. All I can do is accept my condition and do my best to live life fully for my abilities.

10. It really sucks, but life is still good. I’d be lying if I said I don’t have existential breakdowns at 3 a.m. thinking about how I’ll be sick on Christmas, at future family events, in 5 years, in 20 years, forever. But I still find joy in life and those moments mean more now. I love being part of the CPD, owning my home, having a dog, writing, and being married. To all my Fibro and chronic pain/fatigue sufferers out there, I literally feel you and you are not invisible.

*If you are wondering just what that mouthful means, it includes Fibromyalgia, Myalgic Encephalomyelitis, Multiple Chemical Sensitivities and Gulf War Illness. You can learn more about each at the May 12th international awareness day website.