Glimpse into a misunderstood illness; Chronic Fatigue Syndome/Myalgic Encephalmyelitis

Having a chronic health problem is frustrating and horrible. Having a chronic health problem which is yet to be fully understood by medical and scientific explanations is like slamming your head against a wall of nails. The sheer arrogance, ignorance, insensitivity and degradation put towards people with these illnesses is mind boggling.

I recently had a cardiologist tell me that all I had to do was to “change my attitude.” This was based on an extremely brief summary of my current diagnosis and a tilt table test. The fact that he heard the words “Chronic Fatigue Syndrome” was enough for him to summise that I had just got up one day and said “eh, I couldn’t be bothered.” Had he stopped a minute before his relentless lecture, I could have informed him of the years of pain, discomfort and illness I have pushed through, trying to live a normal life and keep going. I could have told him of all the tests and doctor visits I have undergone; all the days at work when I could barely make it though; all the times I’ve blacked out while driving. I could have shown him the out of whack blood results, the kilos of weight loss, the limited diet my body allows me to eat, the signs of physiological stress, such as hair loss and nail ridges. My extremely low blood pressure alone could have shown a cardiologist of all people, that there are multiple physiological issues with my body. I could have told him about all the social events I miss out on, the relationships that have abruptly ended, about the work that I love but can not do, about the mind numbing boredom and loneliness that comes with it all. I could have told him about the endless articles

I read looking for answers; about the hydrotherapy sessions I do each week; about the natural therapies I undertake; about the never ending hunt for something to help me improve my health. It just blows my mind that someone could have such an almighty view of himself to think that telling someone who is chronically unwell to change their attitude, when he obviously has absolutely no idea what my attitude is, was something appropriate or useful. He barely told me the results of the actual test I went in for; he just got lost on his tirade against a condition he clearly does not understand.

I can not for the life of me understand why CFS/ME gets misunderstood. We do not fully understand cancer, yet we see that as a serious condition. We once knew nothing about diabetes, however we have such great treatment for it now. When did someone come along and say, “ok, we as the human race, have learnt and come to understand everything in our environment”? Did I miss that memo? I just do not understand how well educated people can see all the information before them of many, many people with the same symptoms and test results, and not take it seriously just because we are yet to find the bio marker to give us a diagnostic test!! The research is getting so close. There are new articles coming out regularly on CFS/ME research and there are so many clues coming together which will bring us that test. It seems like a professional weakness to me if you can not see that new research will always be happening, and new conditions will be understood. I just hope I can meet that doctor again one day when my blood test results show the diagnostic evidence.

To follow the great research happening into CFS/ME, this is a great site to visit: http://www.mecfs.org.au

Another thing that contributes to the poor understanding alongside the lack of a diagnostic test, is the name of the condition. Chronic Fatigue is such a loosely used term which trivialises the condition. Myalgic Encephalmyelitis is the

less used name for Chronic Fatigue Syndrome. This name incorporates the fact that it is a multi system condition.
If I get asked how my energy levels are, at that moment they might be quite reasonable. Chronic fatigue is not the only issue with this condition. At that moment, I could be dizzy every time I move my head slightly, or the front right corner of my skull may feel like it is ripping apart like a fractured iceberg; my joints and muscles may feel like I am a 90 year old who has fallen from a great height flat on my back; or my concentration is so thwarted by brain fog that I can't remember what I asked as a friend replies moments later. And there are more symptoms with CFS that aren't related to fatigue, such as noise and light sensitivity, and nausea. When you say that you have Chronic Fatigue Syndrome, people can assume you are pushing yourself, that you need a rest, and will often add in that they "are so tired too". The name Myalgic Encephalmyelitis however, demonstrates that the condition has muscular, inflammation and brain involvement (it also appears to have immune, autoimmune, endocrine and autonomic system involvement too).

More understanding of this condition would make the already tough road slightly easier to travel for sufferers. When someone with brain cancer says that they have a massive headache, swelling and feel nauseus, dizzy and tired, people would accept that those symptoms are caused by the tumour, and provide support. When a CFS/ME sufferer says that they are exhausted, in pain, or feel sick etc, they will often be given "it is probably because you slept badly", or "maybe you ate too much." Why is the fact that I HAVE CHRONIC FATIGUE SYNDROME not enough to explain the fact I feel unwell?! I have an illness. That should be explanation as to why I feel unwell.

It seems to me that someone who passes judgment or gives misguided advice on a condition which is yet to be fully understood scientifically, without having experienced it, is

being naive and egotistical. I know I am among far too many people who have to put up with these occurrences on a daily basis. If that is you, know you aren't alone, and one day, we will get a diagnostic test, I am sure of it! Then that will lead to treatment. Have faith. And if you are one of those people who feel you know about a condition you have no experience with, maybe you should reevaluate your thinking and take a step or two in our shoes – if you have the strength.

And with that, my ranting is done! Enjoy your day; keep strong and happy!

