ONE WOMAN'S STORY

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Category: Observations

One of the nice things about using social media such as Twitter, is that you come into contact with some fascinating and inspiring people. One of the people who has most impressed me is a woman who goes by the name of @stroopwaffle on Twitter (she has other names). Stroopwaffle is... well, let her tell her story:

> *After gaining 9A* and 2A grades at GCSE and 4 A grades at A-level (including the joint highest score in the country for one of them), and having been a member of netball, hockey, football, swimming and athletics teams, I arrived at university in September 2004 to study Medicine, a healthy individual. All that changed when I became ill with a virus in my first term there and then BAM:*
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> *This has been my life 24/7 for the last 4 years and 9 months:*
> ***Imagine this:***
> *Being bed-bound and unable to sit up because every slight movement, even talking, causes you to go into heart failure; chest pain and pain in the left arm along with your heart straining to pump; severe headaches that mean even a tiny move of your head causes agony to shoot through it; dizziness so great that it causes the room to swim; muscle pain and exhaustion especially in the arms and legs, making it so difficult to move them; insomnia - 2hours broken sleep per night is about the norm; chronic constipation meaning that you have to use a suppository just to get some bowel movement; painful and swollen glands and lymph nodes; a constant low grade fever; poor digestion and absorption that often causes agonising stomach pain; spine pain; muscle twitching...you get the idea!*
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> ***I don't want your pity.** I want you to understand...and to read on to raise your awareness. This is severe Myalgic Encephalomyelitis (M.E.), which means inflammation of the brain and spinal cord . I am dictating this in the hope that people will listen. I have to dictate it for obvious reasons.*
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> ***My life involves** just about managing to prop myself up enough to eat, getting to the mini portaloo in my room (a remnant from our camping days), shuffling to the bathroom a couple of times a week to wash lying in the bath under the shower. All these "activities" cause my symptoms to get even more severe and I have to lie still in between them in order to be able to do them. My treats involve watching a bit of television from my bed (though audio and visual stimuli are also exhausting) and going on Twitter on my iPod whilst lying flat. I can manage a few tweet a day, but that takes a lot out of me too. Read on.*