

Glimpse into being in my shoes

This morning, after reading tweets written by other people with long term illnesses, I read again the story of "The Spoon Theory." This is a well written explanation of what it is like to not have a body that is firing on all cylinders. You can find the story here: <http://www.butyoudontlooksick.com/wordpress/articles/written-by-christine/the-spoon-theory/>

Even the people who spend a lot of time with me, do not understand what it is truly like to live with an illness that robs you of your true capability. They try to, they think they do, but ultimately they let you down when they expect more from you than you can physically give, and then feel disappointed or hurt by you because you can not give it, when you are just trying your best. I think my mum is really the only person who comes close to truly getting it, without actually going through it herself.

I don't want to use excuses. I want to increase people's awareness of these issues, so there is a better understanding. I have it so much better than a lot of people by far, and I do count my blessings. I do understand the struggle however, and I want to improve people's knowledge of the subject.

As the spoon theory lays out, when you have limited energy reserves, and issues such as pain and dizziness are a frequent occurrence, you have to choose which battles to fight. Sometimes, I will have a shower and it will make me feel better. But a lot of the time, the simple process of getting ready in the morning is so exhausting, that by the time I am ready to leave the house, I could do with a nap! Sometimes, I choose to do something slightly physical, like go to the shops, or do a photography workshop for a few hours. These tasks are gentle, and involve only slow walking, and can even

be broken up with regular breaks. However, they completely drain me. I have to choose to do something like that, knowing that I will be physically and mentally spent by the end. I would rather do that than always rest and do nothing; I want to get out there and live! But the thing that disappoints people, is you do something like that, and then they want you to keep giving more, and you can't. Every bone in my body comes to feel like lumps of hot and heavy stone, and I can barely keep my eyes open, and the dizziness and nausea set in, and as much as I would absolutely love to keep going, the only option is to sleep. I get frustrated by this, but I can feel it, so I know I just have to give into it. People who can't feel it, try as they might, don't know why you can't just push a little more, because their bodies allow them to.

It took me a really long time to learn to give into it. When doctors kept telling me there was nothing wrong, I kept pushing myself. So many days at work, I felt like I had to just concentrate on getting through. That upsets me because I couldn't give my best. Trips to the grocery store were usually a downright horrible experience, and then going home to cook dinner every night was a nightmare! By the end of night, I felt absolutely broken. But then people expect you to keep giving, so you can't stop.

Now that I have been told there is something going on with my body, I have been able to ease off myself a little. I am getting better at accepting help, and asking for it. I am better at saying no, I can not do it. I am better at knowing I need to rest, and fitting it into my day.

What would help now would be more people who understand that just because I can't, it doesn't mean I don't want to. More people who understand that I am trying my absolute best, and yes, it isn't equal to what other people can give at their best, and yes it doesn't fit into what people normally do at my age, but it is my current best. So many people have moved out of my life because I can't keep up with them or give them

what they want; you definitely learn who your true friends are when you decline social offers and the like, and then never hear from them again! This time in my life is bloody hard, and I just don't need people giving up on me; it makes me weaker and the struggle is so much harder. People in my situation come to rely on other people, and when that network gets smaller, although it leaves you with the people you can really trust and count on, it makes you feel insignificant, misunderstood, let down and thrown aside. I do absolutely understand how it would feel for other people though, and I would forgive and welcome them back into my life!!

I am (hopefully!) getting really close to finding a solution to my health problems. I am confident that soon I will be more of the me that I used to be. I really hope so. I will have gone through this, and learnt so much; who is important to me, who I am important to, what my goals are for my life, where my strength comes from. So many people do not have the prospect of getting better, and their motivation to keep going is truly inspiring. Everyone can help each other, with a little trust and understanding, with love and support, everyone can keep people who are struggling going.



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