Glimpse into chronic fatigue guilt – it’s a fine line.

This chronic illness thing can really get you feeling ticked off at times! I feel like I get a grasp on how to handle things, and then something happens and bam, I am back to feeling alone, and unsure of how to get out of this never ending tunnel. I am not writing this for pity. I want people in similar situations to hear this and know they aren’t alone. And maybe our shared experiences can come up with a way of dealing with it all.

Over the past few weeks, I have had a few days where I have pushed myself through, so as to not miss out, and for the most part, it has worked out fairly well. But then I get days when I am completely wiped out. It is hard for me to understand, and harder for people around me to understand. Why quite good one day, and then hiding under the covers the next?

I know from reading blogs from people in similar situations that I’m not the only one feeling annoyed at people saying “oh, but it would be so good if you went and did that”, or “you can’t be in bed all day”. Why would a young person, who was previously very active and loves life, lose out on fun days if it were just a case of mind over matter?! All the things I miss out on make me feel miserable, so why would I do that to myself if it weren’t for the fact my joints ache, my stomach hurts and I feel so tired and dizzy that getting dressed can be an effort?!



I am still undergoing tests, and the unknown factor behind my bad health is very disheartening.



A condition like cancer is something everyone knows, and sees as a reason why you'd be feeling unwell. With lesser known or yet to be diagnosed illnesses, it is impossible for anyone to understand unless they have experienced it. In addition, I often "look well", so people can't comprehend that I feel bad. It is also hard because I don't know how and when this will all end. I have an autoimmune disease, chronic fatigue, chronic postural hypotension and severe food intolerances, but so far, the treatments have not made a huge difference.

I feel like there is a constant barrage of mixed messages. "Rest before you are fatigued and look after yourself" is something I have been trying to accept. I feel like I am

getting there, and then I get messages of “don’t give into it, keep moving, living life will make you feel better”. Which one is it?! You wouldn’t tell someone you has just had their leg broken to get up and run to make it heal! So why tell someone who is so tired and sore that having a shower is put on the back burner because of the effort required, to stop being lazy?!



I can not wait to get back to exercising, socialising, working, and looking after myself. It can not come soon enough! (I am so excited about exercise that I even have a plan of classes and new activities I want to try!). I would try anything to get my body to start functioning properly. The medications I have started are doing a small amount, but not enough. When I do feel up to doing something nice, I then feel guilty because I’m doing that and not doing chores, or going to work, even though I know if I did those things instead, I wouldn’t last.

In the meantime, I have decided that until I know how to make my body better, I am going to listen to it. If it wants to rest, I will rest it. If it wants fresh air, I will walk. If it is up to socialising, I will enjoy it. I can’t feel guilty or lazy. It is unfair that I am unwell; it is ridiculous to be made to feel guilty about it, or that I’m letting people down.I am forever grateful for all the help and support I get from people. There is so much that I can do because of the help I get. My mum is always doing things for me so that I

have energy to do good things, rather than chores. It is a fine line between listening to your body, and being thankful and accepting the support and advice. I am also absolutely keen to try anything, and take part in all that I can. I just know that we all need to learn how to listen to our bodies, and find a happy medium between letting our bodies heal, continuing to live life, not feeling like a nuisance, helping people help you by talking to them about how you feel, and being grateful and appreciative of people's help, and returning it when possible. We need to use the ability we do have and do the best we can with it, accept our limitations, don't use "flaws" as excuses, be kind to ourselves and rest, and make the most of what we can do.

