Glimpse into my thoughts about chronic illness

I have chosen to write 5 things I hate about having a chronic illness, 5 things that help put a positive spin on chronic illness, and 5 things I still need to learn from or about living with chronic illness. I hope this helps people feel less alone, get some ideas, or understand other people's situation…

5 things I hate about having a chronic illness:

1. Missing out. Knowing all my friends are out having fun, and I'm stuck at home. Not being able to exercise. Not being able to make the most of an early morning. Being constantly guided by my limitations even when I do get to do something fun.
2. When people tell me how I feel. "You've had a really good day today". "You've been feeling a lot better lately." "You feel bad because…." Also when people say "that's how I feel too"…Really? Really?? Do you feel endless exhaustion right down deep in your bones, which never goes away even after a sleep – even on a good day, aches and pains, brain fog and confusion, insomnia, nausea…(the list goes on!)?? Oh! Well then, you must have CFS too (or a similar condition), and I feel for you. Otherwise, you are just tired and a good sleep will get you right (lucky you!), or you are not 29 and our bodies' abilities shouldn't be compared and still, you probably just need a good sleep – ultimately, you just don't get what CFS is like, and no, you don't actually feel the same as I do.
3. Feeling guilty. Feeling guilty because people do so much for me. Feeling guilty I am lying on my bed watching a movie, instead of going to work. Feeling guilty that I feel down about my situation sometimes when so many other people have a lot more on their plate to deal with than I do. Feeling guilty that I am not the real me sometimes for the people who love me. Guilty that I cause my loved ones stress and

worry.

4. The uncertainty. The fear that this might be me forever. The worry that no one will want me or love me as I now am. The stress about not knowing when I will be able to return to work, and what that might mean financially in the long term. Not knowing when or how this condition will improve is a constant cloud; even when I ignore it and push it away with positivity, it still lingers.

5. Losing friends. I have had to endure several relationships of varying closeness, wither away or change in dynamic over the years of my declining health. It is heartbreaking, unfair, sad, and distressing. I am not the type of person to just let people drift away. I try my hardest to keep friends close. So when people just lose interest, or can't cope or get frustrated with the way I am because I am sick, or feel pulled down by someone who is unwell, and just walk away or give up, it is really hard to cope with.

God gives us only what we can handle. Apparently God thinks I'm a bad-ass.

5 things that help put a positive spin on chronic illness:

1. Losing friends. Yes, it has been heartbreaking, but the relationships

that I had going into my illness, and don’t have when I come out of this period in my life, are relationships that I ultimately do not need in my life. People who have stuck by me and have helped me instead of hurting me, and those who have joined me along the way, even knowing I was unwell, are the kind of people that I want in my life.

2. Waking up and just being able to focus the day on me and my health. I don’t have responsibilities or deadlines, and I can just do what is best for my body. I am so thankful for all the support I have, emotionally, physically, and financially. It means I can craft to my heart’s content, read and watch movies all day! (something you can only dream about during the chaos of fulltime shift work!) ▯ Developing on interests that I have had but not had the time or freedom to pursue has helped to keep me positive and driven. I have been really enjoying making the most of this situation to improve my crafting skills, to increase my memory keeping, to be inspired by other people’s talents and generally just develop my creativity. It is something that is perfect for my condition, and something I really enjoy.

3. Spending quality time with my parents. They have taken me in and looked after me without batting an eyelid; they have been fantastic. I am so thankful for this time to really get to know them as an adult, and spend time with them in close quarters and enjoy them. Sure, you’re typically not meant to live with your parents when you are nearing your 30’s, but I feel like I have been given a really special opportunity to spend so much time with them.
4. Learning more about me. My strengths, my weaknesses, my desires, my wants for my future; all are becoming apparent to me.

5. I have always been focused on healthy choices, but my condition has forced some pretty strict life changes on me. Ultimately, these have been blessings in disguise, and changes I probably wouldn’t have reached without hitting a health low. My diet is extremely healthy. I have learnt so much about how each morsel of food impacts your body. I am aware of my body’s need for rest and don’t push it like I used to. I know how to

listen to my body. I have realised how positive and negative thoughts really impact. So many things I have learnt and changed that will ultimately make my life healthier than it was before.

5 things I still need to learn from or about living with a chronic illness:

1. I find distraction key to my current condition. I am constantly reading, online shopping, chatting to friends on the net, listening to podcasts, watching movies, looking at inspirational blogs, crafting etc. It takes me away from the aches and pains, and the constant, deep feeling of fatigue, and from the frustration and sadness. Sometimes though, I find, especially when I am alone, that I don't stop and just "be" in the moment, because I am worried about the non stop chatter that will take up in my mind, and the pain and wooziness that will be the only things to concentrate on. When I go for acupuncture and massage sessions, it is nice to just stop. My mind gets noisy, but I am trying to focus on the relaxing music, and the beautiful trees outside the window. It feels like a lose-lose situation, in that if I relax and stop, I will be overcome by my body's faults, but if I keep ploughing on with distractions, I never just fully relax and tune out. It also means not fully living in the moment; life whirls on by! I need to work on finding a happy medium. Distraction from the discomfort combined with living and existing in every moment. Life might not be full of adventure and excitement for me at the moment, but it is the life I am living, so I can't just let it fly on without me.
2. I am realising that I need to start looking at the small gains as

big wins, instead of only seeing the big losses. Being up and dressed by midday is a big achievement for me, and if I start to focus on things like that instead of only focusing on the fact that I am missing out on a gym session or a night out with friends, I can be more positive and motivated, and feel a sense of improvement, rather than constantly seeing what I don’t have or can’t do. It is really hard to do, because when you feel so bad so often, a tiny improvement seems pathetic and unworthy of notice. It feels like recognising them is saying that I am close to the end, but that seems so ridiculously far off. However, at the moment, that is all that I have. Small things really are the big things in chronic illness recovery.

3. I have come a long way in asking for help when I need it, but I probably still am too stubborn in holding onto my independence for my own good!

- I need to try more things that I fear will make me feel unwell but know that could ultimately make me better. Post exertion malaise is a horrible thing to experience. Sure, everyone would feel it after a 10 km run, but after walking up a short flight of stairs?! Or after doing 3 slow squats, or putting away your clean laundry? When such simple things make you feel like you’ve done backflips all the way up a mountain, trying to persuade yourself to do even a simple daily stroll is not an easy task!! But research shows that small amounts of gradual exercise is helpful in conditions like mine. So I need to keep the fear at bay, and step by step I will get to the end prize.
- I want to let myself enjoy life more, even though it doesn’t seem to be the one I ordered!! On “good” days, I sometimes feel guilty about having fun or getting out the house with friends, because I am not at work or helping with the house chores etc. But good moments for my body are usually few and far between, and I am extremely fortunate to be in a situation where I can enjoy doing good things during good moments (thanks to the family love and support that I have, and the financial help from Income Protection Insurance, which I encourage every person, unhealthy or

healthy, to set up). I need to push that guilt aside, as well as the fear and worry that people will judge me or misunderstand my situation. As my best friend says, you put up with a lot of crap times when you have a chronic illness, so if you get to have good times, you should not feel guilty about them. People who are well and healthy may have to go to work and do chores, but they don’t struggle to feel well, so maybe it equals out, and good times should just be enjoyed as good times!!