When making the most of life seems impossible…

People are constantly saying to be grateful for this life that we have been given; this life is a fleeting gift and we need to make the most of every moment. I am a positive person, and always believe that it is important to look for the good, even if it is the tinniest thing when everything else is not so good in that moment. But sometimes it gets so hard to do that when making the most of every moment seems impossible.

A large portion of my time is spent resting or sleeping, and visiting doctors. Watching movies, reading and sleeping sounds idyllic, but when you have no other choice, and you feel horrid while doing so, it is far from the indulgent luxury it may seem. When you have a chronic illness, time and time again you are forced to cancel plans with friends, fail at goals you have set yourself, and miss out on doing things you love to do. You get tired of saying the same reason over and over – "sorry, I am not well enough today…" You feel furious at your body.

The way I would like to make the most of every moment would involve being active, working, being creative, being social, doing things for my family, being independent, and so much more. Subsequently, when my reality is the opposite, and even just sitting to complete this blog post has taken me weeks and is exhausting, making the most of every moment almost seems comical. I am 100% grateful for my family and friends, for the roof over my head and the food in my belly, for my beautiful dog, for the access I have to entertainment and books and to healthcare. But at the same time, I think it is ok for all of us who have chronic illnesses to acknowledge how much it just down right sucks!

I think we hear so much about how we have a duty to realise

how amazing this life is every minute of the day, that we don't know how to really deal with or accept the realisation that, actually, sometimes not every moment has something amazing within it. The constant inspirational speeches about embracing life can leave you feeling even more lost. Sometimes you feel like saying, "ok, but how can I make the most of my life by doing what I love when I can't do what I love?!"

As I said, I do think it helps a lot to look for the good. For example, as I sit here with tachycardia, lightheadedness, the need for my 4 hourly medication kicking in, a headache lurking at the borders, I am also appreciating that I feel pretty good for me. I am grateful for the gorgeous fluff ball who is sitting faithfully beside my feet, and for the memories of the laughs and cuddles from my niece and nephew this morning. I am thankful for the aircon that is keeping some of my symptoms at bay, and for the cup of tea next to me.

But I am also holding onto the fact that I didn't do a gym class this morning that I would have loved to have done before meeting friends for breakfast. I am fiercely aware that I won't be going to work tomorrow, and have no way of contributing to the world. I feel like I have no life plan, no ultimate goal. I know that I barely have any plans this week because it is so hard to set anything concrete in place with an unpredictable body. I resent my lack of independence.

I know that these kind of thoughts produce unhelpful feelings of anger and frustration. But as humans, we have feelings all across the spectrum, and we need to feel them all – that's life. They also make us aware of the things we want to fight for. Why do we go to doctor after doctor looking for a solution? Why do we eat the best foods for our conditions, do physiotherapy, take medications etc etc? It's because we know, deep down, that those things we are missing so much are worth the struggle, and we will do everything in our power to inch closer to them or to an alternative that will make us happy.

So, I just wanted to put this out into the universe because maybe someone reading this might feel the same. Maybe you will feel a little less like you’re the only one experiencing this. Maybe someone will have a great piece of advice, and if so, I’d love to hear it in the comment section below so that we can all learn. Maybe someone without chronic illness will have a little glimpse into what it can be like. And maybe we can all come together and have a little virtual hug!