Living a satisfying life (even when unwell) & changing your expectations

As of today, I have been unable to work for three years. Wow. That is a long time. It took me that long to get my degree for the career I loved! On the day that I had been unable to work for a year, I had a group of friends over with my family, and we had lunch in the sunshine and listened to music. I didn't want it to be a sad or frustrating day; why not have a laugh and see the positives?!

In a previous post that you can read here, I wrote about some of the things that I have learned from having chronic illnesses, and I thought that today I would share some ideas about coping with life without work.

Being chronically unwell is an isolating and frustrating business. It can be easy to lose your sense of self – your place in the world – and fall into a feeling of uselessness, boredom and loneliness. For a long time, I was constantly having thoughts such as, 'well I will be back at work soon', and 'when I just get this medication sorted, I will be better', and the like. Then I reached a point of realisation that, actually, I am not getting better. I have several illnesses that do not just 'go away' or heal themselves, and as yet, science does not have the answers on how to treat them. So eventually, I had to change my state of mind (and it is still a work in progress!). I had to change from thinking 'when this is over and I am better', to 'this is how my life is for the time being, so how am I going to live it to the fullest?' This then lead on to some dead ends and confusion, but ultimately, has put me in a better place. Instead of being in a place of limbo, accepting that this is now your life allows you to mourn what you have lost, and then readjust your

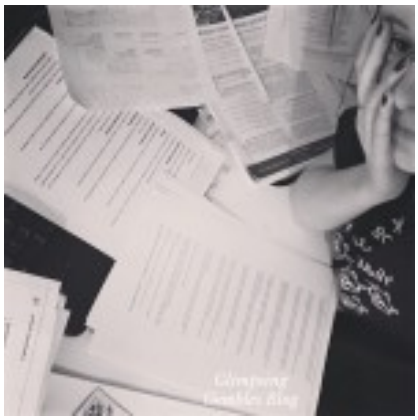
life to make new plans and dreams – and believe me, that can be an exciting and optimistic experience.

At the beginning of 2015, I made the big step to enrol in university part-time. This was huge for me – I was so worried that I would not be able to keep up, that even part-time would be too much, that I'd fail miserably, and that I would make myself more unwell. Fortunately, I have an amazing support team/family behind me who have made all the difference. My mum drives me to and from uni for each of my classes, and waits nearby in case I am too unwell to stay. She does all the everyday tasks and chores so that I can use my small energy supplies for uni and study. SHE IS AMAZING. I generally do not go to the lectures each week, as I found that too much, and I can listen to them online, so I just have two short tutorials each week. Not only is this a place of learning for me, but it allows me time with other people, which is so important when mostly house-bound. I have been studying a Diploma of Arts, majoring in Writing, which has long been a dream of mine that I never thought I could justify doing. I am so grateful that I have been given this opportunity to pursue my passion – great things can come out of unexpected changes in your life path! I had to readjust what I had planned – a career in nursing, 'settle down', have a family – and make it more suitable to how my life is right now.



It has also changed my view on the way our society sets us up for life. The fact that I thought that I could not 'justify' doing something that I was passionate about is crazy, and it is sad that it took me becoming unwell to get me to a place that I could 'allow' myself to do it! From when we are young, we are told to go to school, choose a career (at a ridiculously early stage of life) to do for the rest of our life, earn an income, own property and other material things, have a family…you get the drift. When I look back, I am incredibly happy with the way my life was going. I loved school, I had a fantastic gap-year travelling, and working with people with disabilities, and I enjoyed university and met some of my closest friends there. I worked as a nurse after graduating before travelling overseas with a good friend, then moved to Adelaide and gained some amazing work experience in various areas of nursing. I am proud of the exciting and interesting life I lead, and think I have had some great experiences. Then my health started to go downhill, and my day-to-day life began to revolve around pushing on, and just getting through work, getting through the housework, trying to stay active, trying to stay social, until it all just imploded. I couldn't better myself work-wise, let alone consider pursuing a passion, like further study in writing. Maybe, had I not become unwell, I would have eventually pursued more study – it was in my mind. But for so many of us, the idea of dropping a few hours of work for something 'extra-curricular' like study, even though you may be able to financially justify it, is perceived as not working hard enough or not taking things seriously. WE ONLY GET ONE LIFE!! If we aren't going to do what we are passionate about now, when will we?! I now truly believe that we need to do what makes us happy, not what is expected of us through society norms (as long as it does not hurt anyone else, of course). So whether you are healthy or not, have a good long think about whether how you are living your life is making you happy, and if the answer is no, CHANGE IT.

Study has provided me with an outlet that feeds my brain and keeps my heart happy. It is definitely not easy physically, but it has been worth it. Aside from uni, I try to do things that keep me occupied, rather than stewing on the pain or the feeling of being unwell, or the frustration and loneliness. Ironically, being chronically unwell is a full-time job. There are countless doctor appointments, tests, physio work, trips to the pharmacy, and hours upon hours spent incapacitated one way or another, so it is so important to find things that look after your happiness and inner wellness. I read a lot. If I am not well enough to concentrate, I use audiobooks. I spend hours on Goodreads looking for new book ideas, and on bookshop websites ordering the latest on my to-be-read list! (I justify all purchases by the fact it is research for my writing diploma, ok?!) I have also fallen in love with BookTube. This is a community of book lovers who post all types of book and writing-related videos on YouTube and it is fantastic. There are so many people on there that you can float around until you find people who post videos on the genres that you enjoy. I feel like I am not rotting my brain when watching them either – book reviews are important cultural education!



I think it is so important to find something that gives you a sense of satisfaction and fulfilment. It has been almost unbearable going from a demanding yet rewarding job as a nurse, to barely being able to help with day-to-day chores around the house. It is soul-destroying to feel like you are not contributing to the world. Find something that fills that space. It does not matter how small it may seem. It could be learning one new little fact each week. It could be sending a little note to someone you do or do not know and telling them how great they are and why you appreciate them. It could be setting a goal to walk ten steps from your bed and back, and

then twenty, and then fifty, and then out the front door and out into the world!

Having a career is a rewarding and educational experience, but please do not lose hope if you are now not well enough to pursue it for the time being. Work towards being as strong and healthy, both physically and mentally, as you possibly can be, and the rest will start to fall in place. Keep positive, find something that makes you happy you that woke up each morning, and keep going.