Glimpse into learning to live with chronic illness

Now and again, someone stumbles across my blog who is new to dealing with chronic fatigue, or a friend of a friend points them in my direction for advice. This has made me think that it is time to do a summary post about some of what I have learned about dealing with certain issues so far on my journey.

(I have multiple illnesses, and as it is near impossible to differentiate a lot of my daily symptoms from each condition, this post will be about all the conditions I suffer from – Chronic Fatigue Syndrome/Myalgic Encephalomyelitis, Postural Orthostatic Tachycardia Syndrome, and Hashimoto’s Thyroiditis.)

Do your best to not decondition. I heard this concept as I became more and more unwell, but as my normal level of activity slipped away, and the fatigue, dizziness and pain dominated all situations, I could not see a way of incorporating this. On one hand, I have felt so unwell, that the thought of doing anything physical was out of the question. On the other hand, after many attempts of pushing my way through the pain with the resulting days of severe fatigue, the fear of the wipe out overrode the fear of deconditioning. However, it is so important to consider.

It has been two years since I became reliant on regular resting. In that time, I have lost all fitness, and problems have developed because of the bed rest. For example, I developed Snapping Hip Syndrome and bursitis (ironically, usually a runner’s condition) and back pain, due to sitting and lying for such long periods. This then presents more pain that I have to deal with on top of my conditions. Another example is the general problem of being unfit. Even healthy people feel the effects of being unfit. You feel sluggish, tired, simple tasks are more difficult, your poor muscle tone increases the risk of injury and fatigue; the list goes on. Throw that on top of chronic illness, and you have a chaotic blend.

It definitely is much easier said than done to incorporate this concept when you feel so unwell. I am struggling with it myself at the moment. One thing which I am pleased with is that over the past few months, my walking ability has improved. Going from walking 100 metres and being overcome by the pain, I can now walk my dog for 10-20 minutes and actually (for the most part!) enjoy it. I know that stretching is something that I really need to work on; I need to focus on setting myself an unavoidable daily goal of certain exercises to improve my muscle strength and flexibility; it is a work in progress!

I recommend that whatever stage you are at, go to see a physio. Whether you are in the early stages of chronic illness and still feel that you can do some activity, or you struggle to leave your bed, I strongly suggest seeing a physiotherapist who can recommend exercises for your ability.

Find something which gives you a sense of contributing or self empowerment.
I currently can not work or study, live independently, drive, socialise when I want to; be a normal adult! This leads to feelings of inadequacy, frustration, dependency and an overall sense of being a burden, unable to help self or others. It is so important to find something which gives you something to wake up for; whether it is a hobby which gives you enjoyment, a new skill to master, a pet to look after, or a blog to write. It may seem impossible, and utterly difficult to maintain, but in the interest of self preservation and self esteem, do it.

Acknowledge your limits and accept the change in your path. One of the most difficult things to accept when chronic illness knocks on your door is that things you could once do, you can no longer do, and may never do again. Realising these limits, not only saves you from pushing too far and causing more illness or injury, but also brings you a sense of acceptance and an ability to reassess your goals. Remember that sometimes things need to fall apart so that better things can fall together.

Ask for and accept help.
This can be truly difficult for most people, but your road to recovery and healing hinges on other people helping you.

Asking for and letting them help does not make you weak; quite the opposite, really.

Keep going/fighting but don’t push yourself to breaking point.
There is a fine line between pushing so hard that you never recover or are constantly making yourself more unwell, and being fearful of the negative results and not trying at all. You must live this life as much as you can, so keep trying everything you want to; keep fighting and working hard. However, know when your body has reached its point, and be proud of your ability to stop.

Be around people who are worth your precious energy.
Being so unwell that your normal life unravels, you definitely get an insight into the people around you. Those who will stick by you through anything, those who will pop into your life when it is convenient, those who were only around because they could benefit from you, and now that they don’t, you no longer see them. It is tough, but I am thankful for seeing this. I know who I can rely on. It is easier said than done, but do not let those people who will bring you down with them zap your small amount of energy. Keep the positive people in your life, and do not be too sad when the negatives ones move out of it.

Allow all emotions.
These illnesses are horrible and they take so much away from your life. You are allowed to feel lousy about that. Accept these feelings. Also find the good in the situation too; see the positives and keep smiling. You must keep smiling.

Eat healing foods.
Make educated decisions about what goes into your mouth. Is it helping or hindering your healing process? Is it the best possible choice you can make to feed your body, taking into account pre existing health conditions, budget, availability and access, and what makes you feel good, physically and emotionally?

Explore supplements.
Taking supplements can be important when you suffer from long term illnesses and food intolerances. Research any recommendations and make your own informed choice. Consult nutritionists and naturopaths, pharmacists and doctors, make sure you (and your wallet) are not being taken for a ride, and use supplements and vitamins in collaboration with a healthy diet.

Try out natural therapies such as acupuncture, massage, naturopathy.
A few years ago, I did not give much thought to acupuncture or naturopathy as treatments for illness, and I saw massage as a treat you indulged in once in a blue moon on holidays. However, I am now a regular client of these therapies, and definitely see the benefits. Explore the options which may work for you, be open minded, and reap the benefits.

Sleep is important.
This is of course imperative to everyone, healthy or otherwise. You would assume that having chronic fatigue issues would mean sleep comes easily and frequently. However, a lot of people with chronic fatigue also have problems with insomnia. Even if you get a decent length of sleep during the night, you will likely find yourself waking feeling unrefreshed. I also find that because I spend the day resting, I sometimes feel resentful when it comes to bedtime that I have to end my unproductive day and sleep. This may sound silly (though I often do feel a little more able to function

at night time) but if I feel cheated out of my day because I could not do what I want, I want to stretch it out to its fullest! This then begins a tricky cycle of late nights, so I know I must be careful with this. Ultimately, getting at least eight hours sleep, beginning not too late in the evening, is what you want to aim for. I have written a post previously which looks at sleep and the best way to get it. Read it here.

Socialise.
Keeping in touch with the people who are important to you and the activities and hobbies which you enjoy is so important. It is extremely difficult to do, however. It takes a while to realise what types of events and outings you can handle, and it is also hard for those around you to understand and adjust. I also find that the guilt of being out with friends when I can not work or do chores can often keep me from fully enjoying myself. I dread the moment of bumping into a co-worker and them not understanding how it is that I am not tied to my bed 24 hours a day if I can not turn up to work! However, this is unrealistic. Part of healing and getting stronger is getting out there and doing as much as you can; no matter how low key it is, it helps you physically and mentally. The hours upon hours when I am not well enough to leave the couch are torturous, so to get a reprieve and make it to a social event is a victory, a miracle and a reward!

I hope these points help you a little. I would love to hear your thoughts and experiences, and what you have learned along the way. Feel free to contact me if you have any questions and I will try my best to answer them.