

Goal setting with chronic illness

The hype of the New Year (“New Year, New You” and all that) can be motivating and refreshing. It can also cause alarm and self-deprecation. While one person may be swearing off chocolate and lacing up their shoes ready for a 10 km run, you may be reaching for the sweets jar and curling up on the couch in your track pants with an oh-what’s-the-point sigh of uselessness. For a lot of us with chronic illnesses or disabilities, I think it is definitely a real possibility that all the talk of goals and aspirations can have the opposite effect of the intended inspiration.

The festive season is different for those of us with illnesses. I do not work, but the couple of weeks of mostly-global hiatus brings me a form of holiday. A holiday from doctor appointments, a holiday from medical tests, a holiday from the clinical side of the full-time job that is chronic illness. Unfortunately, there is no break from my faulty body, but the scheduling gap in the constant line up of appointments is appreciated. I am not invited to fun Christmas work parties nor do I hit the town, dancing in festive merriment, and a lot of the festive season is spent quietly as usual. It is, of course, a time of happiness, gratitude and family, and even when unwell, we should all look for those things that are important to us. It may not be the fun whirlwind others experience, or that you may have one day known, but it can still be a pleasant (though bone-crushingly exhausting!) change from the norm.

Then comes New Year’s Eve, and the inevitable contemplation of goals for the year.

I have spent the first week of the year commencing a new medication. Last year began (and continued throughout) the

same way, as did the year before. My life is one big medication trial! The dread that accompanied it this time hung over me during the festive season. The night before I was due to start, I was moping in self-indulgent self-pity, thinking about how unfair it is that for yet another year I am set to be on the rollercoaster that is new medication and side effects.

So how could I think about grand dreams and plans for the year? As much as I'd love to say my resolutions involve travel, exercise, a fantastic new job, and fun experiences, the truth of the matter is, my plans for the year revolve around dealing with another new diagnosis, and working towards the seemingly distant and unreachable goal of independence. For someone in their early 30s, I feel like my plans are 60 years too early. When also dealing with the flare ups that Christmas brings, it can definitely be easy to slip into a feeling of sadness or worthlessness when you think where your life is, when everyone around you seems full of energy and excitement for the year ahead.

I talked in a previous post about how important it is to find things, no matter how tiny, that give you a sense of purpose and achievement. I think it is also useful at this time of year to acknowledge that feeling of the unfairness of your situation. It does help to have a moment or two of feeling sorry for yourself – just don't stay in that moment. Use it as a bolster – hit the bottom and push off with renewed strength and determination.

In my last Blogmas post, I talked briefly about resolutions; mainly about activities I want to focus on more. These involved my blog, my sessions with an exercise physiologist, a plan for my study, and improving my ability to look inward for happiness and strength. Here are a few more things that I want to work on.

- **Ease myself out of looking back on the life I had before**

my illnesses with longing. It has been a part of the transition, but I have now come to the understanding that my life now involves limitations that I have to adapt to, and unless science makes some incredible breakthroughs, this will be my life now. Adaptation is hard to do if you're constantly looking back at what once was, and wondering if it will ever be again. This is incredibly hard to achieve – I loved to be active and one of the biggest things I miss is being able to go out and have fun, whether that be in a gym class, out on a hike, or hitting the dance floor, and there is not really a sufficient replacement for this gap in my life, but I am working on it. I still have a lot to be happy with. I feel like I constantly miss people who moved on without me when I got sick, activities that I can no longer do, goals which I can no longer aim for, but I need to remember to be happy with what I have, because it is a lot more than so many people have in this tough world.

- **Don't let a fear of what others will think stop me from trying something.** A lot of unexpected hesitation and guilt comes along with financial and physical support. I feel like I am constantly thinking "if I do such and such, someone might think I shouldn't be able to do that as well as asking for help." I only get this life, and it is confined by limitations as it is – why impose more by worrying what people (who often don't have all the information) think. Along with this though, I need to remember to not push myself too far. I feel like I have got to the point where I think "well I am going to feel horrid either way, so I might as well give it a go", which can get something done, but can also end with me in bed for days! Balance is key.
- **This year, I want to do more than survive each day.** I try to enjoy and be present in the moment, to see the small things, and do as many of the things that make me happy as I can. Having incurable conditions can be

overwhelming though, and many of us can find we're just pulling ourselves through each day. When asked how things are going, my common response is "oh yea, plodding on", because that is just how I feel – I plod through life because feeling unwell most of the day doesn't lend itself to much else. I look at other people with conditions or disabilities, and some of them have found their niche – something that they can do within their capabilities, and they radiate happiness because of it. I want to find something that makes me more than someone with an illness.

- **Continue to spread awareness of chronic illness and to support others.**

I feel setting New Year's resolutions sets most people up with unrealistic expectations that come crashing down by March. It is important to have goals though, and these can be set anytime throughout the year. Make them realistic but be brave and optimistic about them too. I would love to hear what your current plans are. It may be a plan to get you through this week, or something you want to work on gradually for the next few years. Be kind to yourself, and let your dreams grow within you, and fight with all your strength to keep working towards them. We can do it.

