

CHRONIC ILLNESS

A self-help book that is actually no help with how to feel better, but perhaps will help you to explain how it feels to be chronically ill to family and friends

-Zoe Dunkinson



Life's labyrinth; understanding the journey through life with a chronic illness

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Chronic Fatigue

I use to be quite ignorant when it came to chronic fatigue, I really thought that I understood, not that I ever doubted how hard it must be to be tired all the time. Or thought any less of it than any other illness or condition, I was just ignorant in my understanding. I thought that it would feel how I felt at night after I'd had a long day; really exhausted and more than ready to go to sleep. I never realised that the kind of tired you felt with chronic fatigue was actually a whole different kind of tired to what I had ever experienced. It isn't the kind of tired that you get at the end of a long day, and you sure don't wake up the next morning feeling refreshed, knowing your body has had the whole night to recuperate. It is really NOTHING like that.

It's the kind of tired where you physically just cannot open your eyes; nothing can force you to stop them from shutting. It's the kind of tired where you have to keep moving one of your fingers or toes ever so slightly, just to prove to yourself you are still awake and therefore still in control of your body. It's the kind of tired where you just can't wake up, and you just never seem to feel refreshed. It's like waking up from anaesthetic over and over again.

On the days that it is really bad you can have nap after nap after nap but you never feel any better, perhaps you even feel worse. Maybe it's because you feel awful that you've wasted yet another day or maybe your body has just reached the point where even sleeping is a tiring activity. It's awful and it's really nothing like the tired you get after a hard day at work or school, and it just never seems to go away.

What makes it worse is knowing that no matter how much you sleep you're not helping yourself at all, all you're doing is making it worse. But how do you break the cycle when you're so tired you can't even get up, so tired you can't even open your eyes, and the effects from breaking the cycle are so far to come. It can't be 'cured' in a week or a day it's a much longer process than that. This is what makes it so much harder, because you never feel like you are getting anywhere. It just feels like an endless cycle of fatigue, which in reality is what it is.

The best feeling is when you break free from the cycle for a day or maybe even a week. Even just sitting around doing nothing feels so good, purely because finally you're not tired and you don't have to worry about taking a nap, so maybe you can even go out and enjoy the company of one of your friends!



The exercise battle

One of the treatments for chronic fatigue along with many other illnesses includes gentle exercise. Of course no one ever thought that was going to be easy, why would it be? You are going from hardly able to leave your bed to starting a new exercise regime, so right from the start you know there is going to be a huge amount of commitment. But without a doubt you will have people telling you to wake up an hour earlier every morning so that you can fit in a half an hours walk each day, as annoying as that may be because that is so incredibly unhelpful and almost the opposite of what you need to do you can ignore their advice. After all they have no way of dragging you out of bed to enforce this exercise.

What you really need to do is build an exercise plan that is suitable for your physical ability and build up from there, and there is a definite need for dedication to get you in to the routine of doing some form of exercise each day. Once you are able to push through the non harmful pain of starting something new and have committed to your new exercise program you start to feel pretty good about yourself. You feel like you are on top of your illness, finally, well a part of it anyway.

At least that's what your body has you believing, because its just when you reach this point that something occurs, maybe a new symptom or an unexpected decline in your health that warrants you to take some time off your exercise program. That's when the reality of living with a chronic illness really hits you hard and you realise how much of your life you spend going through seemingly endless cycles.

Finally you feel well enough to return to your exercises and you realise you have become deconditioned in the time you spent resting and have to decrease your reps and start working on building up your fitness once again.

If the decline in your physical fitness didn't make you feel bad enough you probably also experienced the wonderful advice from a doctor or friend who once again suggests that half hour walk each day to get you back on top of your health.

They just don't seem to understand the 'boom and bust' situation, a term explained to me by my exercise physiologist. Booming is how you feel on a good day when you can do that little bit extra activity, however it is more than your physical limitations i.e. the half hour walk, it will inevitably end in busting. This is where you feel absolutely awful hours later, the next day or perhaps even for the next week so you begin to ease off the activity level. Which is absolutely no help to you at all, this is when your life begins to act a lot like a roller coaster with many ups and downs. What you want is a steady pace on a gradual incline; the incline to stabilised health.

Unfortunately understanding this term doesn't prevent the 3 steps forward 2 steps back effect of living with an illness. Because there will always be times when new things crop up and you have to ease off a little and take some time to recuperate, which is what sucks the most. Because despite the fact that you have decided to fully commit to your exercise program, the one that's been tailored to your ability, you can still be thrown off course at any given time.



Feeling like you're going to throw up vs nausea; the difference

Taking a nausea pill can't solve everything. I didn't know if maybe it was just how I felt because no one I explained it to without a chronic illness seemed to understand, but after asking a chronically ill friend I have it confirmed, there is definitely a difference!

You can feel like you are going to throw up without being nauseous, the difference is; when you feel nauseous it's a somewhat similar feeling to motion sickness. It feels like everything inside your stomach is being turned upside down. You also can't bear to look at a phone screen because the brightness just makes you feel so awful. You feel like if you just vomited the feeling would all go away, but also who likes vomiting? No one wants to vomit!

Then on the other hand you have the isolated feeling that you are going to vomit without all the tumbling feelings going on in your stomach. It's more of a feeling in your throat, like you could be sick at any moment and you have to keep swallowing to keep everything down. However it's not so severe and horrible to experience.

There's a difference though right?



'Healthy' Days

Possibly one of the worst parts of being sick is the enigma of a 'healthy' day, because you feel like it's your opportunity to experience all the things you've been missing; however what people don't understand is that even when you have a healthy day, you still have to behave like a sick person.

What does a healthy day even mean? A healthy day consists of less pain, less nausea, less dizziness less of whatever symptoms are regular to you. But what it doesn't mean is you can run and jump and do anything tyou want, unless you want to feel extremely unwell afterwards. Even then you won't even get whole day of doing all the things you want, because you will probably go downhill really quickly.

So basically you have to decide whether having fun on that one day is worth feeling absolutely horrible the next 4 days. And it isn't is it? But it seems worth it in that moment. And that's exactly it, it's worth it for that moment and that's about all. Because you'll regret it when you feel awful the next day, and when you feel awful the day after that. You'll probably tell yourself I'm never doing that again because I never want to feel this awful again. But when it comes down to it you also don't want to feel this alone, this miserable, and this unable to do something with your friends again. So it becomes an endless cycle really.

There will always be regret, no matter what you decide to do. What hurts more the physical or the mental aspects? The boredom or the fatigue? The isolation or the nausea? There doesn't seem to be a better option when

weighed against one another, so all you can really do is pick which one makes you happier, which one you feel more comfortable with and hope for the best, whilst staying within your limitations.



Water as a cure to EVERYTHING!

Have you ever noticed how when a doctor is at loss as to what to do with you they tell you that drinking more water will help, no matter how many times you tell them that you already drink more than the average amount of water per person a day due to the many illnesses and symptoms you face. They always seem to think that adding an extra litre to your day will definitely help you to feel better.

It is as though they think that our stomachs are bottomless pits that we can continue to fill with water. Like somehow being sick has finally got something going our way and one of the 'perks' of being chronically ill is that somehow we have been advanced on the course of evolution to receive Mary Poppins goody bags for stomachs; small on the outside however an enormous space with in. Unfortunately though my stomach does not possess any supernatural water holding abilities, perhaps it's even worse than your average stomach due to nausea.

Surely there is a limit to how much water they can actually prescribe for us, there has to be an amount that is humanly impossible. But then again it seems like they always feel that more water is the answer no matter how much you are already consuming.

So despite the fact that we don't have any additional capabilities of downing 4 litres of water in a day than any other average human; I don't seem to ever see a doctor with a glass of water on their desk. When is it that they drink all this water that is so curing for all our ailments? Perhaps it's unhygienic to have a glass of water sitting around all day in a doctor's room, still I don't

leave my bedside without taking my water bottle with me so surely they could do the same. It would probably be a lot more convincing that it was possible to have a continuous stream of water flowing into your mouth if you witnessed any kind of proof that your doctor also was trying to take up the challenge.

None the less just as I feel as though doctors don't seem to understand the water conundrum, one much similar to the homework conundrum you face when at school. Where every teacher says they are only giving you one hour of homework a night, or every doctor tells you I'm only telling you to drink 1 extra litre of water a day without thinking how many other teachers or doctors you have saying the same thing and eventually it all gets too much. I am grateful for the doctors that do help me and provide suggestions for improving my health, and I absolutely do believe that water is helpful to me provided it's an amount that is within consumable standards.



The fear of becoming nocturnal

When you're younger being nocturnal seems like an interesting concept, it would be awesome to know what goes on while you are asleep, is there a whole other world of people perhaps even living next door to you that you never see purely because you do things at opposite times of the day? Probably not. But as a kid there were endless possibilities of what might be going on during the night.

Although when you're sick the fear that you might be living out your childhood dream of becoming nocturnal is definitely no longer a fantasy but a terrifying fear. At first it doesn't really matter you stay up late a few nights unable to get to sleep maybe watch some videos on your phone or play around on your laptop, but eventually it begins to become worrisome. After a while you realise that your body has become accustomed to falling asleep in the day and being wide awake at night. Depending on how sick you are it doesn't seem like it would be a huge deal though right? I mean if you're too sick to work or go to school and your always too unwell to go out with your friends does it really matter that much when you're awake and when you are asleep?

Until eventually you find out the answer to that question, which is yes! It really matters, it matters when you have to travel an hour to a doctor's appointment, sit around in the waiting room for at least another half an hour and then produce quality answers to their questions about how you've been going since the last time you saw them. This is when you realise that it really matters that your body is unable to stay awake during the day, but has no

problem keeping you up all night, when there are no doctors around so you can't even reschedule your appointment to a time that would be better suited to your new sleeping schedule. Even worse is when you are desperate to hang out with a friend who you haven't seen in ages due to the fact you are always so sick and you can barely stay up long enough to have a shower.

This is when you really start to worry because you realise that to get back to the normal sleeping cycle of being awake during the day (as best as you can) and sleeping at night you're going to have to either sleep all day and then all night or stay awake all day and night to catch back up with everyone else. A task which seems impossible, if it were that easy you would have done it already, not so much to get back into a good sleeping cycle but more so that you could go out with your friends or stay awake through that doctors appointment, and if you thought sleeping for 24 hours was going to be the easier option you realised you were wrong about that too. There is no way your body is going to let you sleep for 24 hours, it's just not, it's going to let you sleep through the day and then when it comes time for bed it's going to wake you up just as it has done for the past 6 nights.

I use to have no idea how you could break the cycle it seemed to just eventually stop, in time you would either have the ability to fight your body to stay awake or fight it to go to sleep and thankfully everything seemed to go back to normal, just as easily as it went back out. It seemed to just be something that would come and go on its own, and all you could do was wait.

I've now learnt that having a normal sleep pattern doesn't just have to be a sporadic occurrence. I've learnt that Sleep Physicians are amazing, and I've learnt that you can alter your circadian rhythm in a very basic manner. However basic does not equate to easy, just like any other treatment majority of it is down to your dedication and persistence.

What makes it so basic is ironically also the hardest part; your perseverance of the process, because that's about all that really required to start making a change. It's not about medication or medical technology, it's another one of

those gradual and slow process treatments. Unfortunately there is no way to force yourself to go to sleep on cue, allowing you to wake up earlier the following day. However the opposite is a possibility, if you set your alarm for 15mins earlier than you are currently waking up, and continue at this time for around 3 days before increasing by another 15mins and repeating this process. Slowly you will start to shift your circadian rhythm, its hard at first, you want to ignore the alarm and continue to sleep, eventually your body begins to get use to it and you wake up before the alarm even goes off. As you begin to wake up earlier, your able to fall asleep earlier at night as well. Another important factor in this, is lighting. No blue light from screens at night, and as soon as you get up sit outside for 15-20 mins to reduce your levels of melatonin that are causing you to feel drowsy.

As I said, its basic but not easy. It's mostly about self discipline, and when you're sick, you often feel amotivation. But it's worth it, once you've put an end to the constant the sleepless nights, all the days of wishing that you were able to see a friend or make going to appointments a fraction easier, that's when it's worth it.



Why I no longer consider showers a relaxing activity

Showers use to seem like an amazing way to relax, I could literally stand in there for an hour absorbing the warmth of the water whilst pondering my thoughts. It felt so good to come home from an exhausting day at school jump into a nice warm shower and let your muscles and mind relax.

However once again chronic illness has proven it can, and therefore will ruin yet another thing. Showers have become an exhausting feat. Even the thought of having one wears me out, because when you really think about it there is a lot to get done. Get undressed, get the water to the right temperature, wash your body, wash your hair; which in its self is a massive task as you are forced to wrestle with shampoo to rinse it completely from you hair.

Once you have finished doing everything that you need to do in the shower, finally you are able to get out. Which is somewhat of a catch 22, unfortunately this isn't where it ends. You still have to spend the next half an hour standing there while you dry your self off including your hair and then figure out what you are going to wear. So when you lay it all out like that, no wonder its tiring, there is just so much to do and all you really want to do is wrap yourself in a towel and go back to bed.

Thank goodness for the invention of plastic chairs, that allow us to sit down while showering and take away some of the pressure due to the whole ordeal. As much as I feel that having a chair in the shower is most definitely adding to the list of things that make someone living with a chronic illness

appear much older than they really are, I'm more than happy to use it if it means I'll be 30% less tired when I get out of the shower had I been standing.

However that 30% hardly takes away from the fact that the whole process is extremely exhausting and once done showering I feel more ready for bed than anything else. Meaning I spend many of my days when looking perfectly clean and my hair is well groomed and not oily at all, in my house, on my own. As opposed to the days where I haven't showered in a disgustingly long time but need to go pick something up from the shops and have absolutely no energy to shower on top of leaving the house.

This is why showers are no longer in my list of relaxing activities but in my list of activities that consume a lot of physical energy and need to be sandwiched with long periods of rest, that is if I get up early enough to fit all that in.



Everyone knows what is best for you

If your illness was not one that you were diagnosed at birth but perhaps one you discovered later in life you will know that the beginning of your illness is when people really show how much they care. Similarly if you have had your illness from birth you will know that the same sort of thing occurs when you first reveal to a new friend that in fact you are chronically ill.

Initially your friends are really empathetic, well the good ones at least. They want to know how all your appointments went, what the prognosis is and maybe even visit you in hospital too, you couldn't be more grateful to have such amazing friends. But then after a while I guess your illness gets tedious because as 'chronic' suggests it's long term and ongoing and you start to realise that along with your health your friends are also slipping away. Your friends begin to change the way they see you from being the friend who is temporarily sick and needs a little extra support, to the friend that needs full time care, even if you don't.

It is about the same time that they stop inviting you out, claiming they know what's best for you, telling you it will be too much for you to go to that party, or sit at that movie theatre, no one bothers to ask your opinion about coming any more. Even if I was feeling horribly sick I think I would rather get the invite and have to turn it down than to never be invited at all, at least you would know that they still cared and wanted you to be around them.

It's also really important for you to make the call and decide whether you are capable of coming or not because it gives you an aspect of life that you are still able to control. Why is this so important? It's because you have lost

control of your health, you have no idea when you might feel overly exhausted or disgustingly nauseous, it just comes and goes whenever it pleases and this in turn takes a way a lot of control over many aspects of your life.

Luckily though you usually get at least one friend who sticks by you through it all, and even though they can't fully understand what it's like they try their best to be there for you. I have found that the more they spend time with you the more they are aware of your triggers and symptoms and maybe they can even tell you're not doing so well before you even admit it to yourself. Which makes you wonder why it was so hard for everyone else, if they had just stuck around too, then perhaps they would also pick up on your cues and be able to help you if need be. It makes you wonder who is more selfish in this situation, is it you or them? Are you selfish for asking them to put a little extra effort into your friendship or are they being selfish for letting you go from the group just because you're sick. I mean after all I'm not asking for resuscitation maybe just some extra rests when shopping and for them to walk a little slower and I'd be able to go too.

It doesn't feel like a lot to ask after all, you didn't choose to get sick and they aren't the ones that have to deal with it all the time. But still they think that they know best and rather than taking you with them they leave you behind. It's really awful and it sucks when you realise that your friendship mustn't have meant that much to them if they are happy for it to end purely because of your medical situation, but when you really think about it, it's probably them that end up at a loss. To my friends that are always there for me and look after me all the time, I feel like I'm forever ever in their debt, and I know that they don't think of it that way, but for me I will always feel grateful for what they have done for me and will always be looking for ways that I can show just how much I appreciate them. As I feel I will be eternally appreciative, I hope that my friendship with them will be eternally giving and caring in return.



Independently isolated

How is it that at the age of a teenager or for me a legally considered adult is it that we can be so isolated when we should have so much independence. Finally we are at an age where we can drive, go out on our own, catch public transport without a parent accompanying, but due to chronic illness that all seems so distant. Living with a chronic illness can take a lot of your independence away, as it may be too much of a risk for you to go out on your own.

But what about all those friends who have their license or are in walking distance from your house, where are they? It's a weird concept to be isolated in a world where we have so many means of transport. When I think of isolation the first thing that comes to my mind is someone living in a remote area where it's a 5km drive just to get to your neighbours house. Or perhaps being locked in a room with a bunch of people who don't speak their language and they have no means of communication.

People take for granted their independence, they don't realise how amazing it is that they can drive anywhere any time they want or go for a walk whenever it suits them. Not only do they not think about how lucky they are that they have all this freedom. They don't think about what it must feel like for you to sit at home all the time knowing that if just one person came to your house for even an hours visit you would wear a smile for the rest of the day.

If just one person offered to take you out, instantly your problem of isolation would be fixed, which is actually amazing. How many things are there not

just relating to chronic illness but any situation that can be instantly fixed, in one exact moment by the action of just one person?

It would be so easy for someone to offer to take you out, perhaps just having them with you meant you were able to leave the house, and if something was to go wrong at least you had your friend ready to call for help. But for some reason that just seems to be all too hard and therefore you are completely alone; isolated.



Making friends with other people who are chronically ill

Once you get to the point in your life that you realise that your friends have left and aren't coming back for you, and due to your illness causing a lack of ability to go out to social events or even work at a place where you can make new friends you might consider a chronic illness group. This may seem daunting, as there is that fear that maybe you're not as sick as the other people in the group and your illness has less validation and therefore you won't have anything in common. Making friends with other people suffering from illness is so much more than that.

Even if you were to never discuss your illnesses with each other, I'm sure you would still find that you had a significantly higher chance of getting along with them than any random stranger you pulled off the street. This is because unlike a lot of other people it seems to me that once you have experienced long term illness you begin to appreciate different things in life. I say different because why do we have to consider them the 'small' things, for you they may be big, I think their importance to you defines their size and meaning more than their importance to society does. You'll probably find that someone living in poor health has seen a lot more TV shows and movies than someone who is quite healthy, and therefore you have a lot greater chance of finding something that you both enjoy and could watch together. Its activities like these that other people may have over looked because they were too busy studying or too busy at work that will really help bring you together. You never know what skills someone has learned while being sick

that maybe they could teach you or you could enjoy together, for example origami or the art of painting your nails without getting it all over your skin, or perhaps they are even champions of foosball. It doesn't really matter what it is, the point remains the same.

Even if the person isn't sick and they are just one of those friends who were happy enough to stick around, your sickness might actually enable you to help a friend in a way that you never thought about before. This is another reason I feel that someone can benefit from having a sick friend. You can help them to destress from their life and show them how to stop and enjoy the 'little things' that they may have been missing whilst trying to keep up with a busy schedule. You can show them how to smile not because they got a new job but because they learnt how to dominate in monopoly (although I guess anyone who learnt how to do that would be overjoyed) so maybe something else like just being able to enjoy learning how to play a new card game.

However if you do choose to be friends with someone who is also chronically ill and don't make a pact to never bring up illness you will find so much pleasure in being with someone who really understands what it's like to be ill. Even without having the same illness as each other you will discover that there are so many things you have in common, so many symptoms, so many experiences that all overlap. This is one feeling that even the best of healthy friends cannot bring.



How hard it is to have a commitment

How many times is it that you find someone telling you how much better your life would be if you just got a hobby? But what they don't seem to realise as great as it seems it's not all that easy. I'm not sceptical about hobbies, I'm not claiming that there are none out there that sick people can enjoy, there are plenty of crafts you can do from the comfort of your own home, possibly even your own bed. But they don't really give you the same happiness that you get from a hobby that you participate in with other people, such as a weekend sport or drama club. This is the kind of pleasure and satisfaction that the suggester of getting a hobby thinks you will gain.

Again it's not that simple, you may not be able to even participate in a sport any of the time let alone every weekend. It's really hard to commit to things because you never know when you will feel well enough to go and this in turn starts to narrow down your options. Firstly you have to find a hobby where being absent every so often or for long periods of time due to suffering from an episode of being acutely unwell won't impact on anyone else in the group. Secondly you have to decide whether it is worth paying the term expenses knowing that you won't be able to participate in every session. Of course there is also the matter of finding something that is within your physical abilities and limitations, so things are really starting to narrow down.

So you begin to wonder what's left for you to join. Knitting club? So you decide that you are fine joining knitting club because at least it gets you out of the house, and being away won't impact anyone else in the group, the worst that could happen is your scarf ends up being half the length it should have

been, but you decide that doesn't matter because the point of joining wasn't to gain a scarf, the point was to find a hobby and get an instantly better life, as advertised by one of those people that thinks they know best. However when you arrive you realise that no one your age is in knitting club and it's just you and a bunch of retirees who have nothing to do with all their spare time during the day, so decided to take up knitting again as similarly to you they are sitting at home bored out of their brains.

Once again you tell yourself it's ok because at least you have some people to talk to as opposed to sitting at home where the most interaction you get is when the sun is shining through your window and perhaps you get to see your own reflection staring back at you. This is until they begin to ask about your life, and why you aren't in school or university and you realise that a hobby really isn't going to fix everything, something you always knew deep down and the only reason you truly went was so that you wouldn't have to hear about how great your life could be if you just took up a hobby any longer. In fact maybe it even made you feel worse because now you feel even more isolated from people your own age after hearing all those questions and pondering your own life.

I'm sure there are some great hobbies out there, even if they are just at home or you convince a friend to come over and make some cupcakes with you. But for goodness sake would people please stop trying to convince me that going out and finding a hobby is going to cure my health. I know you are trying to help, and without trying to sound horribly rude but with all the time I have sitting home alone believe it or not I have had a lot of time to think about this myself, I also know my own body and situation quite well and what I can participate in and what I cannot. I would really rather not sit at home bored, this isn't a decision I have made, I didn't sit down one day and think you know what would be fun? Doing nothing every day! However if after that you still believe that having a hobby will really be life changing for me will you please come over and do something with me, because that is what I really need; good company.

One of the other downsides of not being able to commit is the lack of holidays you can enjoy. For some being sick will actually prevent you from going anywhere as you have lifesaving medical equipment that you just can't transport, but for others it's not quite that literal. There is nothing stopping you from packing up your bags and driving off to wherever it may be. The problem is more that you won't be able to enjoy it, at least not to the same extent as everyone else.

By the time you get there you are probably so exhausted that all you really want is to sleep for the rest of the holiday, in which case you think so why did I come? Not wanting to upset the rest of the travellers by sleeping all day and not participating in the activities they have planned you drag yourself along. What I find is it's really hard to say no, whether it be because you actually really want to join in with the activity or because you just feel guilt ridden if you don't spend time with your family or friends, it's just really hard to say no I can't do this. Annoyingly the same principles apply for organising a catch up with some friends.

I just wish there were more things in life that were spontaneous, so that I could wake up on a day that I was feeling well and I could call up a friend and they would be ready to do whatever it was that I had in mind. Not even, I'd be perfectly happy for them to pick the days adventure, purely because it would be 100 times better than spending another day alone at home. At least then I would know that I'm feeling well enough to do it, it's nearly impossible for me to tell someone in advance if I will be well enough to do whatever it is they are inviting me to, no matter how much I would really like to participate.

The same goes for work, is there a part time job that I can apply for where I can just work, when I feel well enough, I don't want regular shifts. I just want to call up that day and say "I'm well enough to work today do you have anything for me to do?" This way I'm still earning money, participating in the community and feeling a purpose in my day but there is no anxiety

around what if I don't feel well when I have to work or what if I can't find someone to cover me in time. Surprisingly enough as much as work is tiring and a lot of effort for me to do, I was so glad when I did have a job to go to because without it I'm literally sitting around all day everyday with nothing to do, and I don't know how I could cope with that. For awhile I was lucky to have provisions with in my job that allowed me to maintain my position at work; something that made time go that little bit faster.

Unfortunately I don't have that anymore, my fears of sitting around, nothing to do, staring at walls all day are my reality now. I only worked maximum 4 hours a week, you wouldn't believe how a seemingly minute amount of time spent at a job each week would have such an impact on my life.

Maybe it was the job I had, rather than having a job itself that made the real difference. I was a coach, I took kids to competitions, I watched them progress their skills whilst helping them build the confidence required to try new things. I wrote lesson plans and end of term reports, at the time they seemed so tedious, definitely wasn't my favourite part of the job, but it added to the 4 hours. These were things I could do at home, at my own pace, and they were things that I did for a specific reason, they had a purpose, and they gave me a purpose too.

Not only did I benefit from the time dedicated to work that decreased the time I now spend bored out of my brain. I also benefited from the friends I made, even talking to the kids and their parents. You can spend a week or so without having a 'formal' catch up with a friend and still you probably see, colleagues, customers, patients, clients, uni or school friends/acquaintances, multiple family members, friends in your weekly sport or activity group. Don't underestimate how much those seemingly unimportant social interactions really mean, it's a lot more than you would think.



Those teachers that never seem to get it

Don't you wish that it would be completely acceptable to give a handout to all of those teachers that never seem to understand what we are going through that went something like this:

Despite the illness, which you can't really help, it's school that's worrying me. If only the hardest part was being away, because all you would have to do was come back. But it's not, the hardest thing is coming back, and that's something I have to do. It's hard to watch when your friends are getting stronger and you stop belonging. It's hard to watch yourself fail under the weight of the pressure; it's like looking into a mirror when your self-esteem has been warped, you don't want to believe what you're seeing is really you. You want to believe you're still the confident student who produces work to be proud of, but you're not. All you are is an average student who is further behind than you could ever begin to fathom. Of course your solution would be to make a schedule and catch up with the work. But is it really that easy?

It's not easy to get out of bed and come to school again, or follow routine, it's not easy to come face to face with the peers you have not seen for quite some time. It's not easy to answer their questions, it's not easy to look in the faces of teachers who want so much from you, but

you have nothing satisfactory to give, it isn't easy to stay awake long enough to do the work you've missed. So I guess it's not that simple and I guess my best isn't a good enough best. But it's all I have, and I want to succeed. I just don't know where to go from here.

I wish I could be that studious pupil who has time to add a sparkle to her work, and I wish wasn't sick, and I really wish that I could catch up. But that's not how life works. Life works when you give it the gears to go around, I'm just struggling to get them back in place right now. But I want to finish, and I want to make it to the end. So I'm going to try and I'm going to try hard. Because I want something to be proud of and I want to say I overcame at least one of the hurdles in my life this year.

I am trying.

Nonetheless even if you were to give out a letter that went something like that, even if you gave it out every time it seemed like your teacher or coordinator just didn't seem to understand, it wouldn't really help, because it's really hard to understand what it's like unless it has happened to you. But I guess in the end it's not really understanding that we seek, you don't need to understand the illness to be helpful to someone that is sick, all you need is for that one teacher to show empathy and help you get through, because in the end it will be worth it, no matter how hard it was to get there. Even if you have to do it all alone.



Year 12- University

A section not so much about sickness, but finishing year 12 without achieving what you really wanted

University offers you something that high school never could. In high school, you're basically put into a funnelling system where you are given all these options at the start, nothing too specific but there is a fair amount of variety, and from then on you just have to keep narrowing down what you want to try. There's never an option to go back and try something new, you basically have to weigh up your options and whatever comes out on top is what you do, and there is no real looking back.

So maybe you never really get to try something that you might end up really liking because you picked something you knew that you liked to begin with, or thought that you would like, over picking something else. But there isn't a lot of room to move once you've made a decision. However university is kind of the opposite, you can do whatever you want, stop and start as much as you want, go back for new things as many times as you want. You basically get to build your own education system and it's the same with TAFE.

So I guess in the end, high school didn't serve a whole lot of point in directing you towards your career. It's a pretty narrow path you don't get to try any of the options that are out there really. It's kind of just teaching you how to go through the education system, how to study, how to sit exams etc. But it's never going to get you to your career. Even if you did all the 'wrong' subjects you could still get in to a course somehow and do what you wanted to do, and get the career you always hoped for.

Really you can change your mind as many times as you want, because now you're out of high school it's never going to matter again, there's no limit, there's no well you didn't do year 12 language so you can never learn another language, of course you can. There's always an option to do more and swap courses till you find something you really enjoy.

Missing out on parts of your high school education puts you in a similar position to someone who chose subjects they didn't like or didn't do well for some reason unrelated to their health. It doesn't matter a whole lot, I mean I'm not belittling the system, and of course there is a benefit to high school. Learning how to study, do exams, write essays, and learn all the basics, the building blocks for your education. You also get the social benefits of being in a structured community environment. But in terms of exploring careers options and seeing what's out there and I guess 'making it in the world' it's not particularly helpful.

It serves different purposes, which don't ever really seem to be expressed. People think high school is the be all and end all, but it's more like the preparation. If you don't prepare for something it's going to be harder to do but it doesn't mean you can't do it.

I don't think high school is pointless in fact I think everyone should go to high school granted it's the right system for them. But no one should ever feel like if they don't achieve what they wanted to achieve, or discover what career they wanted to pursue in life, that there is nothing out there for them, because it's just not true. No matter what the reason is that year 12 didn't turn out how it was 'supposed to,' sickness or anything else it might be, there is always a pathway after year 12.



Quotes

"We must learn to live as brothers or perish as fools."

– Martin Luther King, Jr

I recently heard this quote and although I know it was said with a meaning quite different to the interpretation I'm about to give I like it anyway. In my opinion this quote can be applied to living with a chronic illness. How? Well I think just as we have to learn to live as brothers with a whole range of ethnic groups, we need to learn to live as brothers with our illness. We can't fight the fact that we have one, it's not going to change anything. Reality is, is that it's there and it's a part of us. Which brings me to the second half of the quote "or perish as fools," I think this is equally important due to the fact that if we don't learn to accept our illness we won't be able to truly look after ourselves and cater for our medical needs in which case we may just perish as fools. Looking after yourself is a really important part of being ill, whether it be taking your medication or taking time to consider your mental health and the effects it is having on you due to your physical condition and visa versa. This is why I think that this quote can be applied to living with illness as it speaks true to that as well as its original meaning.

I also think that the reinterpretation of this quote is a metaphor in itself as it shows that nothing in life is black and white, there doesn't have to be one way to look at things, especially with an illness. Sure I have picked out the tough aspects of living with a chronic illness but I've also tried to finish each section with a less sombre tone as I believe that you can still find happiness

whilst living with an illness. But the point of writing all this wasn't to make people feel like living with a chronic illness was any happier or gloomier or any easier or harder, it was purely my opinions on what it was like, that would hopefully help people explain to others what it's like to be constantly sick or in pain.

I am including some other quotes that I like, that I think reflect well upon living with a chronic illness but am leaving them without interpretation, because I think quotes are most important when you connect with them yourself, It's about how they make you feel, not how they are supposed to make you feel or how someone tells you they might make you feel. So they may mean nothing to you, but I have included them purely because to me they do, and perhaps they also will to you.

"Remember how far you have come, not just how far you have to go. You are not where you want to be, but neither are you where you used to be."

-Rick Warren

"It's ok to be scared. Being scared means you're about to do something really, really brave."

-Mandy Hale

"Hardships often prepare ordinary people for an extraordinary destiny"

-C.S. Lewis

"I am stronger than this challenge, and this challenge is making me even stronger"

