

# My experience of chronic fatigue syndrome

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## ABSTRACT

A personal story of my journey.

### ANONYMOUS 16-YEAR-OLD

Chronic fatigue syndrome (CFS) is exactly what it says on the tin: it is an extreme tiredness (loss of energy and motivation) which can lead to extreme difficulty or an inability to complete basic functions. Other symptoms include sleep problems, problems thinking/remembering, headaches, dizziness and heart palpitations. As you can imagine, these symptoms have a severe impact on a person's life and often lead to a sudden or extreme change in lifestyle (eg, time outside, time in bed, time seeing friends, etc).

The severity of CFS can often fluctuate and people with CFS typically experience a 'boom and bust' cycle, in which they have 'boom', a sudden burst of energy and (as a result) activity followed by a bust, a period of worse than usual fatigue and extremely low levels of activity.

CFS isolated me to my bed where I often had no energy to move, to talk or even to think. If I ever had enough energy to leave my bed, it would only be for an hour or two and I would often spend double or triple that time resting up again before I could consider leaving my bed again. The fact that I spent basically all day in bed meant that by night-time, although I still had no energy to do anything, I was not physically worn out enough to sleep, meaning for some time I was practically nocturnal. It also meant that school was almost impossible to attend: I missed several terms and had an attendance rate of 20%. Schoolwork—which I could rarely attempt to complete—would take three times as long as usual; it was as if I were mentally trudging through treacle in subjects in which I was previously able to sprint through.

Sadly, CFS is not limited to physical characteristics but can also impact people mentally and emotionally. Feeling like you are slowly losing the life as you knew it; being isolated to your room; unable to see friends/family; and missing out on activities/events can often lead to low mental health, and existing mental health issues can be exacerbated by not being able to talk to people or attend appointments.

The lack of energy to take care of yourself can also harm your self-esteem. CFS can be especially isolating if those around you do not understand what you are going through and because (especially as a teenager) people are quick to label you lazy rather than recognise how much you are struggling.

CFS has a tendency (like most illnesses) to seep beyond the already horrible symptoms, into every aspect of your life: hobbies; friendships and relationships; career or education; etc, many of which (without energy) you cannot maintain. And these characteristics do not get replaced by new ones: they just disappear, and slowly your life can feel as though it is as small as your bedroom. For many people suffering with chronic fatigue not only can you experience a complete loss of energy, but you can also experience a complete loss of self. For example, before CFS, I would say that a large aspect of my personality was my humour (my ability to make those around me laugh), but with CFS I was often so tired I often could not talk let alone think of any jokes.

The treatment of CFS is incredibly effective if people are able to access it. My treatment took place over regular video calls, not only because of COVID-19 regulations, but also in order to make the treatment more accessible to those with CFS.

My treatment came in the form of energy management, which is the process of sustaining energy levels by preventing the 'boom and bust' cycle, followed by gradual increase in energy levels. This means you have to meet your baseline even on bad days and try not to exceed it even on good days. Managing the 'boom and bust' cycle involves a lot of relearning the basic rules to healthy sleep/resting, many of which you probably take for granted or even ignore if you are not struggling with CFS. These include having a set bedtime/wake-up time, not napping for longer than 30 min, maintaining a good bedtime routine, stopping work early, resting regularly, etc.

To start managing your energy, you must first establish a baseline of energy by tracking your activity (hour by hour) for a few weeks. The baselines are often surprisingly low, for



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example, my baseline was 4 hours. You also (through tracking your activity levels) identify particular areas or circumstances that might drain your energy levels quicker than other activities. For me, I found that activities that triggered my anxiety quickly drained my energy. You then slowly build up your energy levels, with the help of CFS therapists, at a slow rate of around 10% every 2 weeks (or however it takes for this increase to become sustainable), this could, for example, be through adding a 5-minute walk.

I also learnt the importance of interspersing rest into my high-energy activities, and also the importance of actively resting. Before I thought that resting was just lying in bed or meditation (both of which never really worked for me), but I actually found that activities such as reading a book or listening to music helped me rest and recharge much better.

Because of treatment, progress that I never thought possible has occurred within a short period and it has impacted every aspect of my life. Despite not being all the way there yet, I can definitely see the target within reach, whereas I previously did not have enough energy to open my eyes. And although struggling with CFS has been so incredibly difficult, I definitely feel like I now have a much better relationship with my body: I can listen to what my body needs and look after it and myself in the process. Certain things like your body telling you it is tired is very important to listen to, whether you struggle with CFS or

not. In order to maintain a healthy and sustainable level of energy, you must work with your body and not against it.

### MY SUGGESTIONS (TO YOUNG PEOPLE WHO MAY HAVE CFS)

Do not be hard on yourself: even if you were not able to do anything today, you still got through today, and that is fantastic! You are not lazy or lacking effort, you are ill.

Try to get some help. If you had a broken bone, you would not hesitate going to a doctor for help, and you should not for CFS, especially as treatment has a similarly high recovery rate.

Finally, please know you *will* feel better soon.

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