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Long Covid - the invisible disease

Hi there, my name is Clara, I'm 18 years old and passed my A-levels this year. Sounds easy, but it wasn't a walk in the park...

For those who are not familiar with the topic of long-haul covid or post-vac syndrome, here is a short explanation: Long-haul covid is a disease following a covid infection. Post-vac syndrome, on the other hand, is a reaction to the covid jab. Both diseases can massively impact and change the lives of those affected. Heart problems, shortness of breath, difficulty concentrating, memory loss, joint pain and exhaustion (fatigue) are just some of the symptoms that millions of people suffer from. But what exactly is this illness and how does it affect everyday life?

My story begins in January 2022, when I got my third covid jab for maximum protection against the virus. Shortly afterwards, I became very ill. I initially thought that it was covid as most of my classmates also had it at the time. However, all PCR tests came back negative, as well as the antibody test in my blood that I had done a few weeks later.

Once recovered, I went back to school. At first, I was quite careful during PE so as not to get myocarditis. We started doing athletics at the beginning of March. I always loved doing sports and used to be a middle-distance runner. Therefore, I was very worried when I had difficulties breathing after just the warmup. The breathlessness got from bad to worse, and I had severe chest pain as well as a violent cough.

This was the beginning of my medical odyssey: Cardiologists found some fluid around my heart, pneumologists helplessly observed how my pulmonary function and lung capacity deteriorated at every appointment. I was prescribed three different inhalers, which worsened my health condition so much that I was no longer able to walk up the stairs in my house. GPs prescribed autohemotherapy and all kinds of capsules, which also didn't help. I had breathing therapy to enlarge my lung capacity and many other procedures and treatments. All the medical experts I saw were at a loss, some even tried to persuade me that it was all "in my head". Even after X-rays and scans of my lungs, no doctor could explain my breathlessness - it was as if the disease was invisible.

I got covid for the first time in September 2022. I've never been as ill as during those two weeks. I had every symptom imaginable: nausea, dizziness, chills, fever, aches and pains everywhere, etc. I didn't even have the strength to go to the toilet on my own. Two weeks after my recovery, I realised that I was constantly exhausted and couldn't focus at all. These symptoms then developed into brain fog and chronic fatigue. The fatigue severely restricted my school attendance. I was able to only attend lessons a couple of days a week. On top of that, my immune system completely collapsed, and I was very ill every fortnight.

I missed more and more exams and lessons and was totally overwhelmed. After the Christmas holidays, I decided to take a break from school because I simply couldn't cope physically and mentally. My condition went downhill over the next two months. My mum even had to help me get out of bed every day because, no matter how long I slept, I was too exhausted to get up on my own. I then started oxygen therapy and osteopathy. The latter helped to improve my energy levels, as did a microcurrent device called Arc4health.

After thinking long and hard about whether I should go back to school at all, I decided to not give up and instead to try to pass my A-levels together with my friends the following year. I worked out my own timetable with the school, which included three to five lessons max a day. In the end, however, I only made it to school three times a week at most, with a sickness absence of 60%. The school arranged for me to not be graded until May so that I would have enough time to catch up. This meant that I had just six weeks until the end of the school year to get the 40 grades required to pass year 11.

During this time, I also started neurofeedback sessions to alleviate my brain fog. Thanks to my doctor, I was allocated 40% more time in each exam. This was quite helpful, but I still had to get grades in subjects that I hadn't attended for a good 6 months. I constantly had oral exams to pass, even on the last day of school when the whole class had already broken up.

In the new school year, I had to skip the school trip to study for a maths exam and two other exams remaining from the first half of year 11. Shortly afterwards, I got covid again, but thankfully it wasn't as bad as the year before. This time though, covid affected my digestive system. I suddenly became lactose intolerant. From that time onwards, every time I had an (even mild) infection, I could tolerate dairy less and less.

In mid-November, I finally had passed all the exams for the whole of year 11. The A-levels were getting closer, and I had to try to attend school as much as possible. I managed to miss only three exams in the whole of year 12, had a full class schedule (8-ish hours a day) and went to school four times a week. What an improvement!

To support my immune system, I started doing weekly IV drips. I was able to focus more, had less word finding difficulties and an overall better memory. It was still all quite stressful, but my condition improved, my sickness absence was down to 40% and I found it easier to keep up in some of the subjects.

On June 28th, I officially passed my A-levels (Abitur). I was so relieved and happy to have made it despite all the odds! 10 days later, I went on our school trip to Corfu. I was quite nervous as I was unsure whether I would be able to join in the fun without pushing myself too much and getting a dreaded “crash”.

Two days before the end of the holiday, I became seriously ill (I couldn't go to the toilet without holding on to the walls, that's how weak I felt). I had a high fever, felt dizzy and slept almost all the time. A local GP put me on antibiotics which enabled me to get on the flight home. Once I had recovered, I noticed that I constantly felt sick after eating and that my stomach was very bloated after each meal.

My condition gradually worsened over the summer holidays until I had to live on rice and baby food. This meant that I was basically starving for three weeks because I couldn't eat big quantities and because the baby food didn't provide me with enough calories. The gastroenterologist that I saw found nothing that would explain my condition. After three weeks, I finally got better thanks to acupuncture, a careful balanced diet and a special gut treatment. Unfortunately, I now can't eat dairy and gluten on top of that. If I accidentally do, I suffer from severe symptoms and pain.

Today, long covid still affects my day-to-day life. However, I have learnt to deal with everything and know what to do when I have symptoms. I also still need to plan at least two ‘days off’ every week to lie down and rest. My long covid journey is far from over, but I have learnt a lot about myself and have already come such a long way.

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