



Living with Long Covid:
A Young Person's Glossary

Long Covid is when people experience symptoms linked to a Covid infection that carry on, or come and go, over long periods of time.

These symptoms have various medical terms, but not everyone might have heard of these or know what they mean. So, as young people living with Long Covid, we have produced a glossary which explains these medical terms and describes what these symptoms are like and how they actually feel.

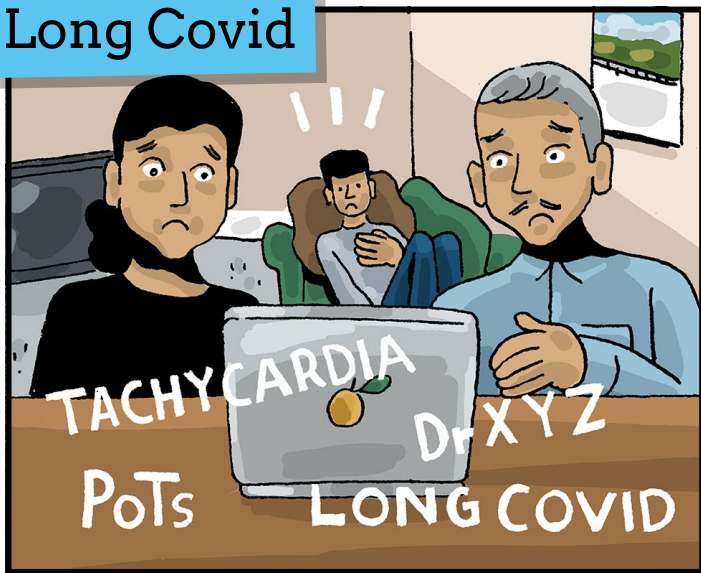
This glossary has been co-produced as part of the Covid Made Long research project. It contains young people's descriptions of Long Covid symptoms, alongside definitions based on the latest information from WHO, NHS and Long Covid advocacy groups at the time of writing. As knowledge about Long Covid develops, these definitions are constantly evolving.

This glossary accompanies a three-part graphic series called Long Covid Lives, which explores the lived experiences of young people living with Long Covid. You can read Long Covid Lives here: www.lshtm.ac.uk/research/centres-projects-groups/covid-made-long#lived-experience-resources

If you are experiencing ongoing symptoms following a Covid-19 infection that last longer than 4 weeks, or that disappear and then return, contact your GP for advice. Early support can be beneficial for symptom management and recovery.

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Long Covid



“It feels like an overwhelming and confusing set of symptoms to navigate.”

“It was like a domino effect - different things keep occurring in my body. I wasn't aware of like how bad Long Covid could be. For the first like few months when I was bedbound, I genuinely thought that my body was like slowly dying.”

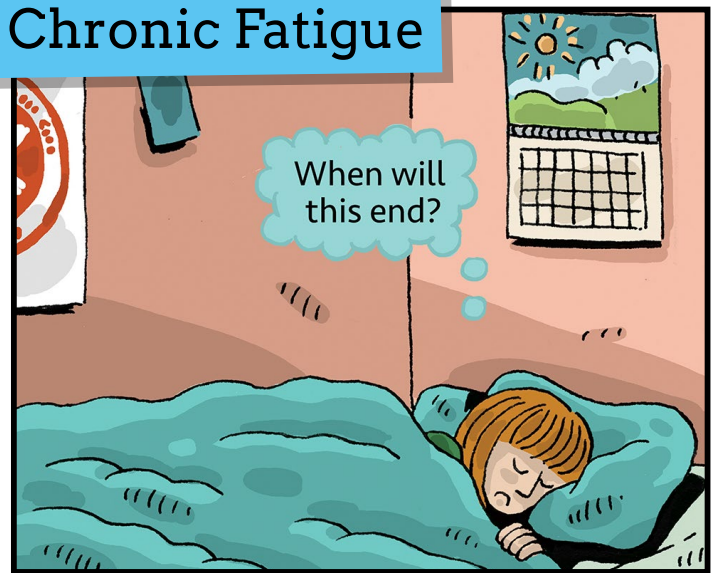
Long Covid is an umbrella term that describes the range of prolonged symptoms that can follow an acute Covid-19 infection. Typically, the diagnosis given by the NHS after 12 weeks is Post-Covid-Syndrome.

Over 200 Long Covid symptoms have been identified. But the most common are fatigue, cognitive dysfunction (brain fog), dizziness, and pain.

You can find out more about Long Covid here:

www.nhs.uk/conditions/long-covid

Chronic Fatigue



“This feels like extreme tiredness, where you need to curl up and rest after doing everyday things which wouldn't have a big impact on most people. It's like trying to walk straight under water when you have loads of waves trying to push you in different directions. Or like having a hangover, the flu, all these things at the same time. It can feel misunderstood soul-destroying and draining.”

Fatigue is a common symptom of many chronic illnesses. For many with Long Covid, chronic fatigue is overwhelming, persistent, and debilitating. It is more than being tired. It is better described as extreme exhaustion that is out of proportion with exertion and not relieved by rest. This is sometimes referred to as an 'energy impairment'.

Post-Exertional Malaise

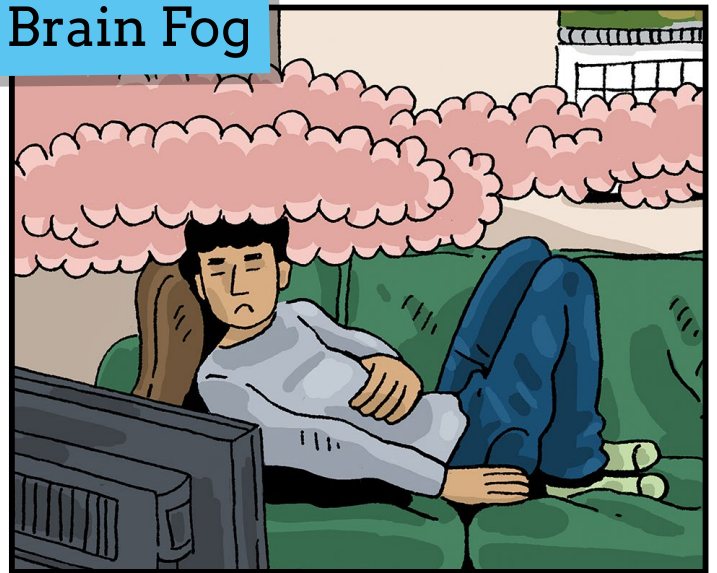


“PEM feels like all of your symptoms are directly linked to your fatigue level. When you use more energy than you have, all of your symptoms increase alongside your fatigue. A feedback loop forms where you grow more tired and unable to tolerate further symptoms, but your symptoms rapidly increase.”

“It feels like your body has been poisoned. Your limbs are heavy, you feel nauseous and have a ‘tired but wired’ feeling.”

Post-Exertional Malaise (PEM) means that it is harder for the body to recover after exertion (physical, cognitive, psychological or social), resulting in a ‘crash’, which can involve flu-like symptoms, as well as increased sensitivity to noise, movement, and light. This often occurs 12 – 72 hours after the activity which triggered the ‘crash’, although it might occur later, and can last hours, weeks or months. If someone has PEM they should manage their energy carefully and not push activity past their limits.

Brain Fog



“Brain fog is like a roadblock in your brain. It feels like wading through mud in your mind, which affects talking as you struggle to think of words fast enough.”

“Imagine you were reading a book and then suddenly a grey, formless ooze covered the pages, stopping you from reading ahead and from returning to what you have just read.”

Cognitive difficulties, often called ‘brain fog’, are a common symptom of Long Covid.

Some common challenges include:

- Difficulty paying attention
- Difficulty concentrating
- Poor memory
- Slower processing, which means you may find keeping up with conversation challenging

Joint and Muscle Pain



“My joints have been quite a lot more painful since Long Covid. I always used to be someone that exercised an awful lot, and now, I’m not even sure I would be able to if I tried. I can get symptoms from just walking to the shops.”

“I can’t do the full day out and about on my feet anymore. I can feel my legs shaking and kind of like going from under me. I used to be able to spend the whole day from beginning to end just walking around and now I just, I physically can’t ”

Sometimes people with Long Covid experience joint and muscle pain. You can find out more about pain management on the ME Association website:

www.meassociation.org.uk

For some people, joint and muscle pain might be linked to Fibromyalgia.

For more information:

www.nhs.uk/conditions/fibromyalgia

Migraines



“Migraines are not just a ‘really bad’ headache, it’s a whole bodily sensation. It can last for days and causes nausea, light sensitivity, eye pain, and vision problems. In my case, this feels like your head is exploding and the only thing that will prevent it is clutching your head and squeezing your eyes shut.”

Sometimes people with Long Covid experience migraines. This is described by the NHS as a very bad headache with throbbing pain:

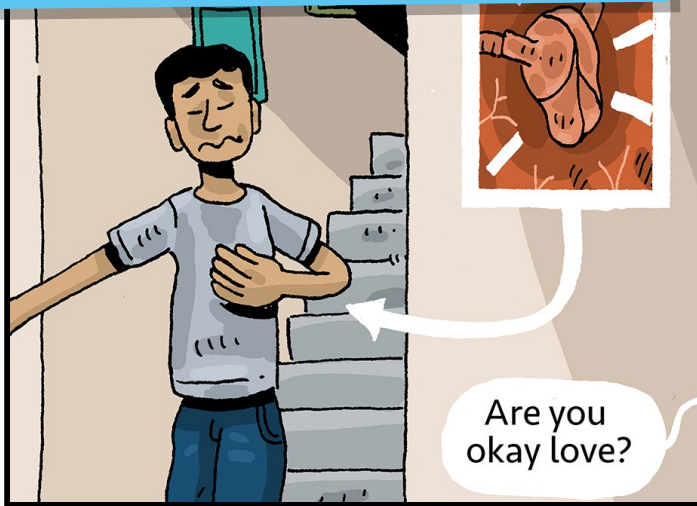
www.nhs.uk/conditions/migraine

Some people get a warning that this is about to happen by experiencing “Aura”, such as visual disturbance, dizziness, pins and needles, or difficulties speaking.

You can find out more about pain management on the ME Association website:

www.meassociation.org.uk

Dysautonomia and PoTS



"My heart starts to go so fast I can feel it in my ears. It feels like I can't stand up. When I pass out, sometimes it can be just completely blackout, so I can't hear anything, see anything. Sometimes it can just be my eyes, so I can kind of still hear what's going on, but I just can't see anything, and sometimes it's more like I just can't keep myself awake"

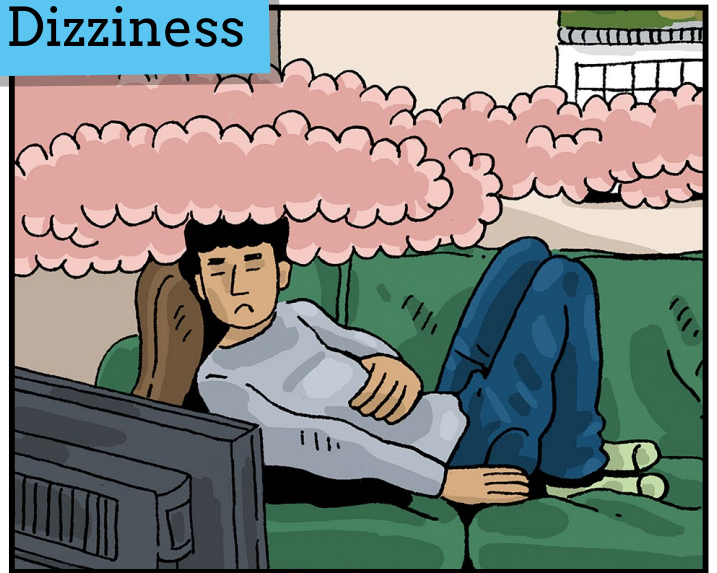
Dysautonomia is an abnormality of the autonomic nervous system that controls bodily functions we don't usually need to think about (e.g. breathing, blood pressure, etc.)

A common symptom of dysautonomia following a Covid-19 infection is tachycardia - a fast heart rate. This can be a constant fast heart rate (IST), or an abnormal rise in heart rate when moving into a more upright position (PoTS – Postural Orthostatic Tachycardia Syndrome).

You can find out more about PoTS here: www.potsuk.org.

And find out more about dysautonomia here: www.dysautonomiainternational.org

Dizziness

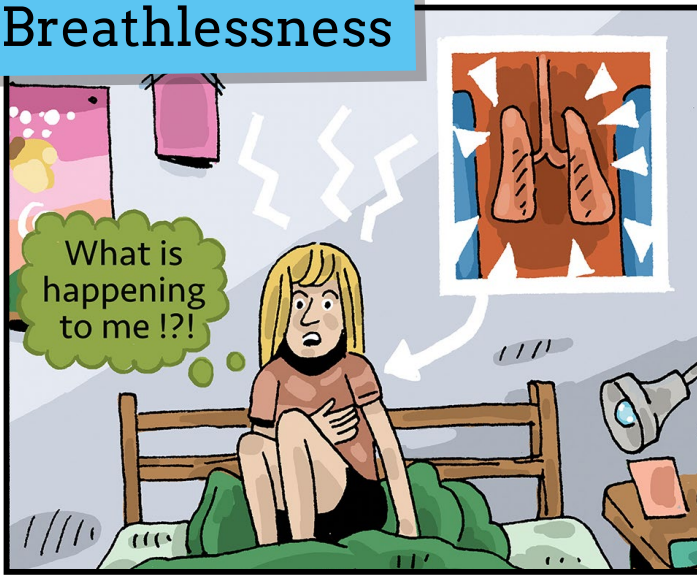


"I was so dizzy I couldn't sit up for ages, I couldn't function. I was just laying on the sofa, I couldn't really do anything. It almost like felt I was constantly on a rocking boat... Just rocking, rocking, rocking."

"I'd often feel quite dizzy, I'd turn my head and it was like my brain sort of had been left behind back there and it's the weirdest feeling"

Some people with Long Covid experience dizziness. This could result from PoTS or dysautonomia (see previous description), which also impacts the nervous system.

Breathlessness

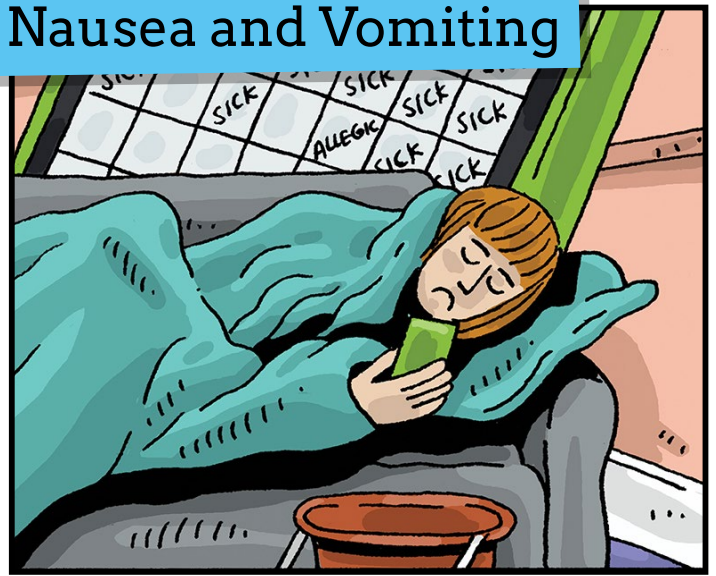


“I picked up the trumpet and tried to play, and had a burning like shooting pain through my chest and could barely breathe. This then went on for a few months, and I’d find myself like almost collapsing from the pain, then realising that the pain was sort of there just when I breathed, and it hasn’t gone.”

Sometimes people develop breathlessness, tightness, soreness, and pain or burning in the chest as part of their Long Covid. Some people also describe being unable to catch or take a breath properly.

There can be many reasons for this. For example, it could be a ‘breathing pattern disorder’ or part of dysautonomia (see previous description). Some people also develop or experience worsening asthma after Covid-19.

Nausea and Vomiting



“It feels like your stomach is in constant pain, as if a band is tightening around it, and you’re almost always feeling at least slightly nauseous.”

“Everyone knows what occasionally vomiting feels like, but with Long Covid nausea/vomiting can be more extreme, and last for an extended time period.”

Long Covid can impact the gastrointestinal system, meaning people feel sick, experience stomach pain, or have diarrhoea and/or vomiting which can be frequent or extend over long time periods.

Severity can vary, with some people finding that this symptom affects their ability to get sufficient nutrition through eating and drinking.

Loss / Change of Taste and Smell

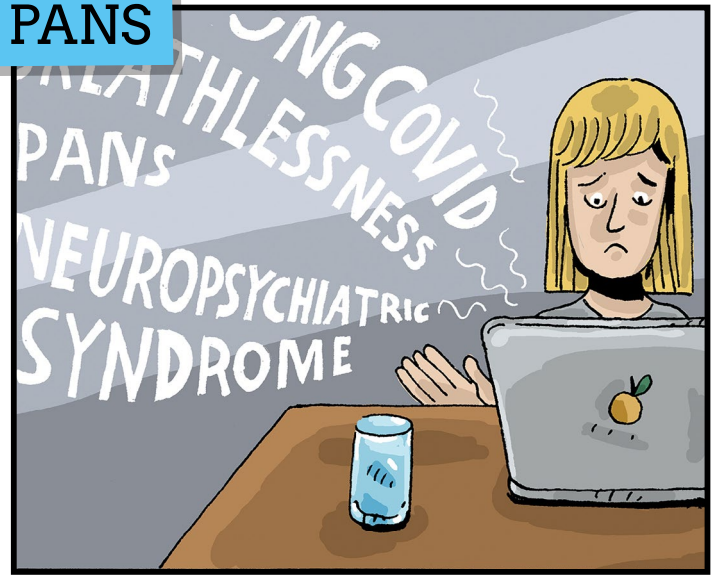


“This feels very disconcerting and confusing, making you worry if it will ever improve. When your taste and smell come back, it can be in completely changed ways, becoming strange and almost always nauseating. It feels like you can’t trust your own senses.”

“My taste started changing. I love mangos, and then when I had Covid I really hated mangos. When that changed, everything else started changing. So some of the foods became a bit more bland. For me it was like six months to a year. I really love food so for me that was just like, ‘ahh, everything’s the same’. It did actually impact how I live my life.”

A loss or change to your sense of smell or taste following Covid-19 may continue in the post-acute stages of the illness. This can be very debilitating and can affect someone’s ability to get enough nutrition through eating and drinking.

PANS



“I developed a stammer and tics. It was like there was a switch that had been turned off or turned on. Tics aren’t fun, they really hurt because they’re like a body jolt.”

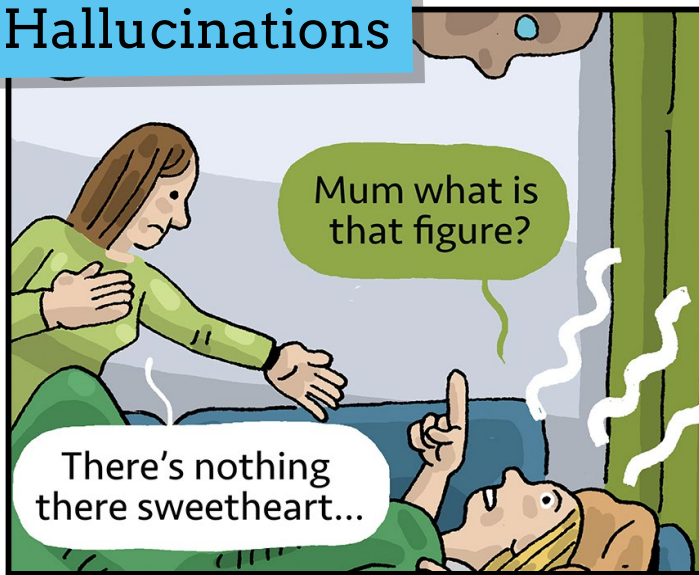
“If there’s like a loud sound you’d like jump. I’d then, for like at least an hour, will be in like a sort of semi fight or flight response, like it just completely sets off all my like literal adrenalin”

Paediatric Acute-Onset Neuropsychiatric Syndrome (PANS) is a condition that can affect the brain through inflammation and is thought to be caused by an immune system reaction to common infections, including Covid-19.

There are lots of symptoms which can include obsessive-compulsive behaviours, tics, eating restrictions, changes in mood and sensory sensitivities.

More information can be found here:
www.panspandasuk.org

Hallucinations



“They’re scary. I do have to try and tell myself, ‘that’s not a real person and they’re not there’. It is a lot more like when I’m very tired and I know I’ve done too much, but it kind of is always present...The most common one I get is a fly which is just flying around the room. The more tired I get the more eccentric and scary they get.”

Hallucinations can occur as part of PANS (see previous description). This is where you see, feel, smell or taste things that may appear to be real but only exist in your mind. Auditory hallucinations means hearing sounds or voices that other people don’t hear.

Find out more on the NHS website: www.nhs.uk/mental-health/feelings-symptoms-behaviours/feelings-and-symptoms/hallucinations-hearing-voices

Sudden Onset OCD



“OCD isn’t just obsessing over a light switch. Imagine sitting down to read or play video games, but all you can think of is the intrusive thoughts that replay inside your head. Often, the only way to get rid of these thoughts is to perform a particular ritual. It could be washing your hands a certain number of times, counting to a certain number or, sure, flicking a light switch. It can steal enjoyment from every aspect of your life and is more than being a ‘clean-freak’, or a quirky personality trait.”

Sudden Onset OCD can occur after a Covid-19 infection as a result of PANS (see previous description) and is an inflammatory response to viruses that impacts the brain. Someone experiencing OCD has obsessive thoughts and compulsive behaviours that can significantly interfere with daily life. Find out more here: www.nhs.uk/mental-health/conditions/obsessive-compulsive-disorder-ocd

Taking steps to prevent further infection from viruses, such as wearing masks, can be mistaken as OCD by some people who don’t appreciate how severely impacted someone with Long Covid can be by viral infections.

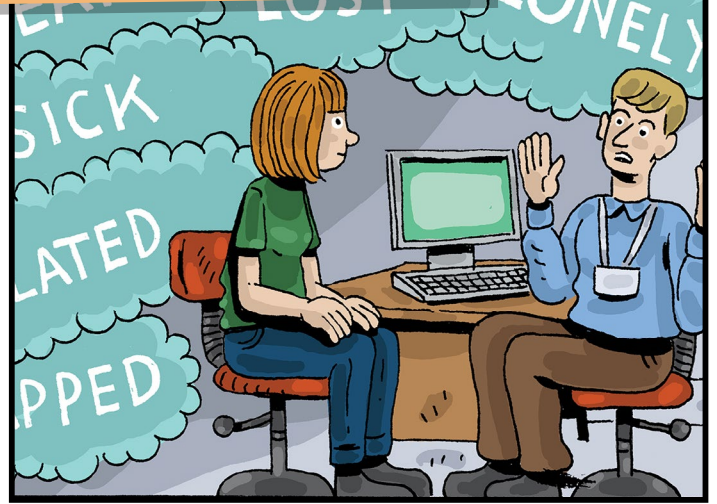
Sensitivity to Light



“It feels like light is straining your eyes or making them tired. Migraines mean that light causes splitting pain and avoiding bright light becomes a must. Any light brighter than a phone screen on lowest brightness will cause me to involuntarily squint my eyes to avoid the sudden pain in my brain.”

Sensitivity to light means that bright lights, like sunlight or screens, can hurt your eyes or give you headaches, even if they don't bother other people. This can occur because of PANS, or migraines (see previous descriptions). Some people with chronic fatigue syndrome (CFS) may not be able to tolerate light at all, so they may need to have the curtains closed, lights off and wear an eye mask.

Long Covid Clinic

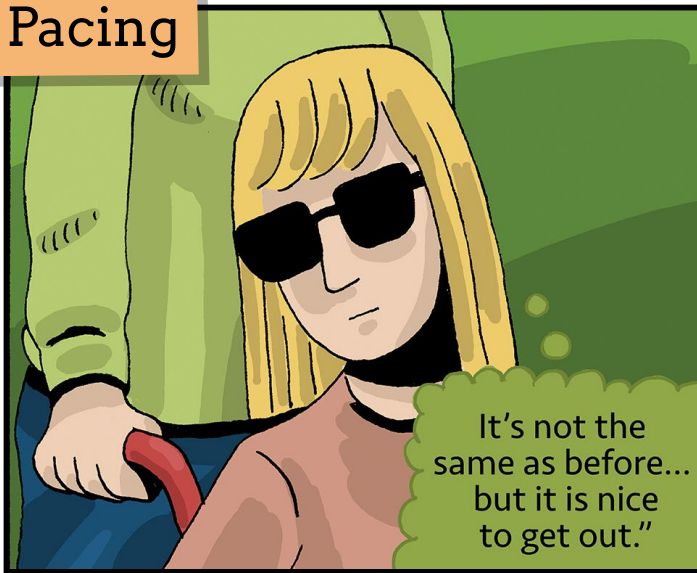


“The Long Covid Clinic did an assessment of my symptoms, and then I had a few further phone calls with them. They offered a fatigue clinic, looking at like sleep hygiene, and diet. I got referred to neurology through them, and a dietician through them. Which were both really helpful.”

Long Covid Clinics are NHS funded services which specialise in supporting people to manage Long Covid symptoms.

Each clinic is different but usually has a multidisciplinary team of health professionals to provide assessment and support.

Pacing



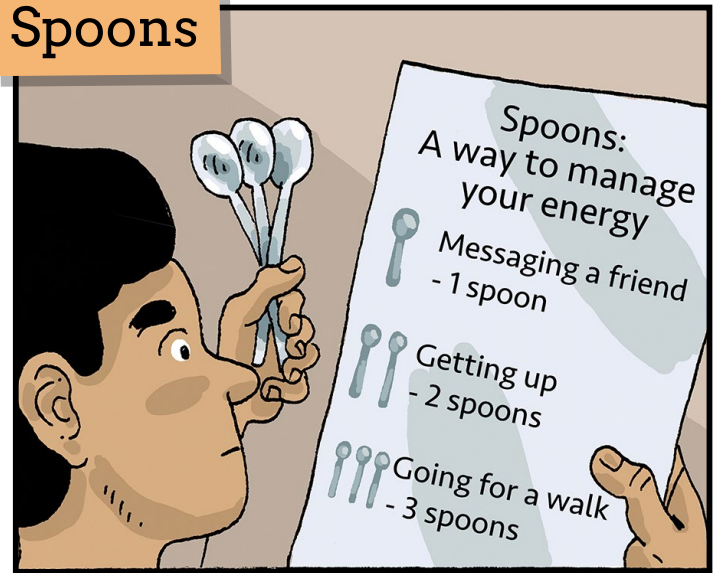
"If you're feeling better one day, there is lots of temptation to be like 'I am going to do all the things that I couldn't do yesterday'. But if I did all of those things, I would feel worse afterwards. So, trying not to use up all the energy at once and then crash again."

"I rest in school. There are study places where you're not supposed to talk, so I go there. I listen to music, it takes away the unfamiliar and unpredictable sounds of the surroundings, and just lets me kind of switch off and rest quite effectively."

Pacing is a way for people experiencing energy limitations or fatigue to manage their energy. This means not taking on too much and prioritising activities throughout the day or week to make sure enough time is built in for rest. It can also involve adapting activities so that they take up less energy, like using a mobility aid, or stopping for regular breaks.

Pacing is not always easy, and it can take some time to work out how to pace activities. Sometimes, activities are too important to avoid even if there is a chance that they impact on energy levels afterwards.

Spoons



"You've got 6 spoons per day you can use and like 3 spoons are taken just getting out of bed or whatever. If you go into spoon deficit then you're going to have a worse day tomorrow, that's the way I look at it."

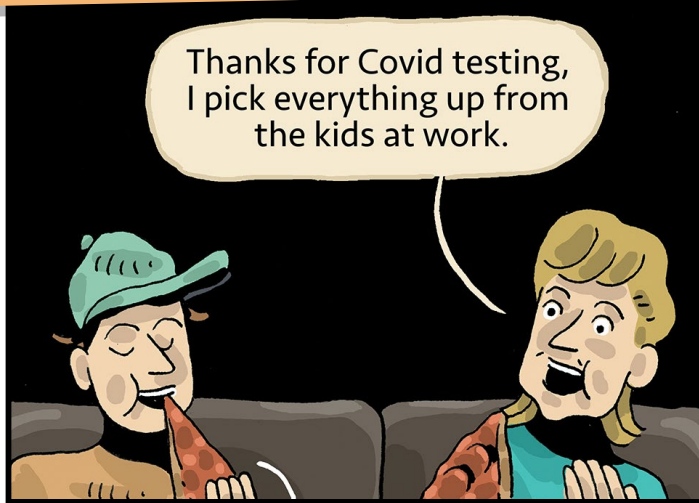
"I've been able to monitor daily how much I can pace myself depending on how many spoons I have. I have to think of what I can do that doesn't take as much energy. So, creating stuff and drawing is what I spend most of my days doing. I try and do a 10 minute walk every day, but there will be days where it's a bit too much. I stick to what I think I can do on a day."

Spoon theory is a concept that is used to help people with fatigue manage daily life and activities.

Imagine your energy per day as a number of 'spoons' and every activity you do uses up a number of spoons (how many can vary by person). This helps people to think about 'pacing' activities to balance their energy throughout the day.

As fatigue, pain, and energy can fluctuate, the amount of spoons you have overall can vary day to day.

Precautions



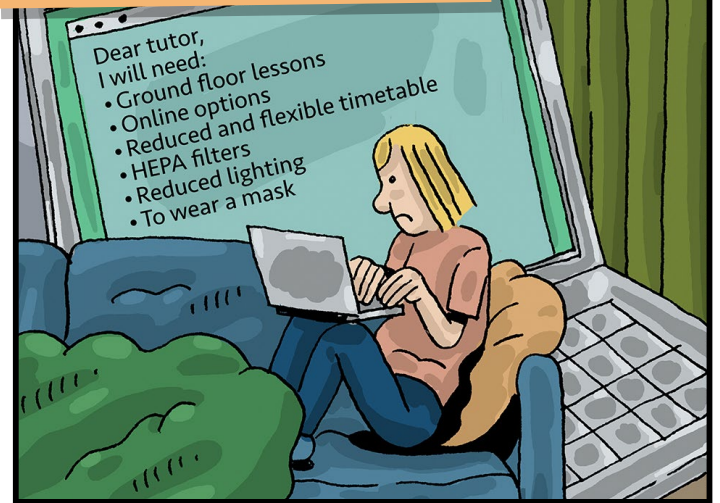
"I work as a nanny and I end up catching everything that the kids have. When it was lockdown they didn't mind me wearing a mask at work, and then after, they were a bit like, why do you want to wear a mask? But it saved me once with a family that all caught Covid at Christmas. It was all worth it because I didn't catch it... When I apply for a job, I say, 'Is it okay if I wear a mask?'"

"I don't walk round with a mask on all the time. We have to be careful of getting infected. We now don't go to places where there's lots of people. Like even when we went out for the meal we were near a window. I think we were quite aware of, you know, that there is a nice airflow."

Some people with Long Covid take precautions to minimise the chance of getting reinfected with Covid-19 or other viruses.

This might include things like wearing a facemask, social distancing in public spaces, using air filters which remove virus particles (sometimes called HEPA filters), or regularly Covid testing.

Accommodations



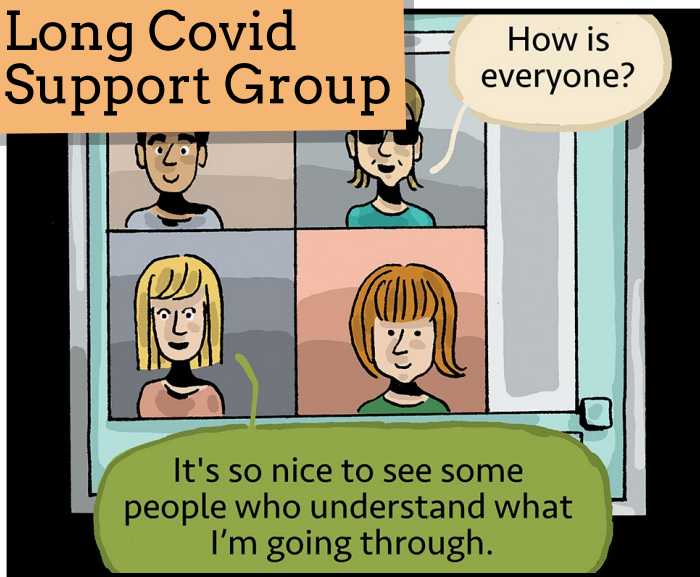
"My tutor allowed me to be able to go in whenever I feel like it. I could leave at any point during the day if I could feel the brain fog and the headache building up. They also allowed me access to their nurture room, which is a very quiet room which helped me stay in school but recover from a particularly challenging lesson."

"The managers at the supermarket where I work have been understanding when I do get ill, which then makes me more short of breath. I'm just like 'I'm not doing the trolleys' and, yeah, they seem to be pretty understanding. If they're in a position to, they'll get me onto a till instead if I'm really not feeling great."

Accommodations are adjustments that people with Long Covid might need to be able to participate in everyday activities whilst experiencing ongoing symptoms.

This could include things like having a reduced and flexible timetable at school, uni or work, having access to space to rest during the day, or being able to join activities remotely.

Long Covid Support Group



“Facebook groups were my introduction to the fact that there were so many people that also were struggling. I was so isolated from anyone like understanding what I was going through. People were telling their stories about what they have and what supplements they’ve taken or what results they’ve had from the doctor. I was able to like figure it out that way.”

There are various peer support groups available for people with Long Covid. These groups can help people share tips and tricks and find others who understand their experience.

You can find some of these resources here:

- Long Covid Kids: www.longcovidkids.org
- Long Covid Support: www.longcovid.org

Social Support



“My brothers have been my two closest friends throughout this time. They’re always there for me and make me laugh, so make me feel normal again, not somebody who’s been well, sort of stuck in bed for ages.”

“I recently got into a relationship, and that’s helped me so much, to be encouraged by someone.”

“My mum comes to the doctor’s appointments a lot, she does like most of the cooking, cleaning. If I’m in a period where my symptoms are more severe, she’ll help me with like washing my hair and things that I find too exhausting to do.”

Social connections like friends, family, or partners can be an important source of support for people with Long Covid, especially when it can be challenging to access help from formal services.

Forms of social support can include staying in touch, checking-in, or finding more low-energy ways to hang out. Or, supporting with everyday tasks like cooking or cleaning, helping to coordinate medical appointments, or navigating systems to access additional support.

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Long Covid Kids and Long Covid Support

The logo for Long Covid Kids, featuring the words 'LONG COVID KIDS' in a bold, uppercase, sans-serif font. The word 'COVID' is in a larger, bolder font and has a red dot over the 'i'.

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