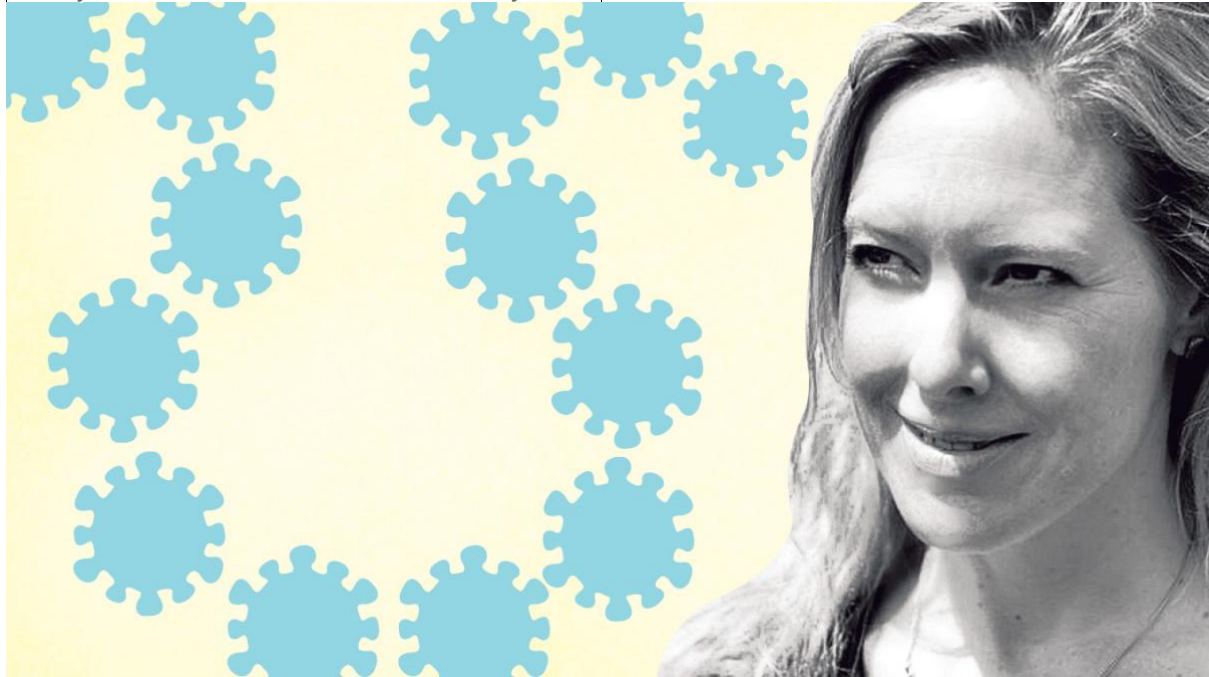


Long Covid: The nightmare a million of us still can't shake off

Britain is learning to live with Covid-19, but for thousands, the debilitating effects still linger

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Emily Kate Stephens has been on a “corona-coaster” for 23 months

It is a surprisingly common dream: you are trying to get somewhere, but your legs will not move. “It’s like wading through treacle while wearing flippers,” according to Emily Kate Stephens. This is her reality — everyday tasks have become workouts.

“On bad days the smallest jobs can wipe you out for the day: hanging laundry or even going downstairs. Making sure the kids are wearing the right uniforms. I open the fridge but my brain can’t picture what to cook.

“I didn’t speak to most of my friends for a year because I had no capacity for anything outside what was imperative. Sometimes, walking my dog for ten minutes leaves me with full body muscle tremors for a week.”

Until March 2020, the 43-year-old lived a high-functioning life, working 40-hour weeks as a producer and raising two children. She swam, cycled, skied, surfed and did yoga daily. Then she was hit with a moderate bout of Covid-19. “I was in bed for a few days but didn’t need hospital,” Stephens said. This was to be expected of a virus that hit older people with additional illnesses hardest.

“Three weeks later I had this massive crash while I was out for a run. I was in bed for five days,” she said. Since then, she has been on what she calls a 23-month “corona-coaster”. She had to leave her job last February. “It’s like being chronically hungover,” she said. “Except I’ve not drunk anything since 2020.”

Thanks to Britain’s high levels of immunity — and a less deadly variant of the virus — the chance of hospital admission from Covid is about one in 200. The chance of dying is about one in 3,000. We cannot prevent infections altogether, so we have learnt to live with them: since the first Omicron case arrived in November, about 16 million people have caught it in the UK.

Yet there are hundreds of thousands like Stephens who — despite avoiding Covid wards — have been rendered incapable of functioning normally after contracting the virus.

The number of Covid infections in Britain will remain high for the foreseeable future. Will the number of “long Covid” sufferers keep on rising too?

Poor health and economy

There has been much scepticism about the number of long Covid patients in the UK (or “long haulers” in the US), not least because of how the condition is defined.

According to the Office for National Statistics, 1.5 million people — about 2.2 per cent of the population — had long Covid symptoms over the new year, many times

the number who have died. The symptoms include fatigue, shortness of breath, loss of taste and smell, and difficulty concentrating (often termed “brain fog”), but also palpitations and nausea.

This measure is far from perfect. It is self-reported: there is nothing stopping people from exaggerating symptoms, or misattributing them to other conditions. It also includes anyone who has symptoms four weeks after an initial infection. Some people may feel groggy the following month, but will get better — when does Covid end and long Covid start?

About 1.1 million people in Britain reported [symptoms 12 weeks after catching Covid](#), which is generally agreed to be the cutoff. Rates are highest in northeast England, where 2.5 per cent report symptoms, and lowest in Northern Ireland at 1.2 per cent. One in five — 205,000 people — say their symptoms reduced their ability to undertake day-to-day activities “a lot”.

The effect on business is showing: a survey by the Chartered Institute of Personnel and Development found that a quarter of employers said long Covid was a “major” cause of long-term absence.

The size of the economic hit is nearly impossible to forecast. According to Julian Jessop, an independent economist: “If 100,000 people were unable to work due to long Covid, that would be 0.3 per cent of the workforce. In addition to the reduction in the supply of labour, productivity is likely to be hit by staff absences. A total hit of 0.4 per cent of GDP would cost the economy £10 billion a year.”

Robin McNelis is the leading physiotherapist for long Covid at the private Wellington Hospital in north London. “A third to a half of people I see are not back to working the way they were before,” he said. Nearly 3 per cent of health and social care professionals report long Covid symptoms, the highest rates of any profession.

“I know lots of nurses who used to pick up extra shifts,” added McNelis. “About 25 per cent of shifts in ICU [intensive care units] were done by nurses doing overtime. Now, too many have had Covid and are permanently drained. It’s not that all of them are stuck in bed — they’re just not firing on all cylinders.

“One of the patients I reviewed yesterday, a nurse, has just turned 55. She’s going to take out a pension because that’s a better option.” The healthcare system already faces a workforce crisis.

Many of the patients McNelis treats are “high-flyers” — people at the peak of their physical fitness. He knows a lawyer with the condition who was assessed walking at just 4mph. They struggled to speak afterwards.

Indeed, the risk profile of long Covid sufferers appears to be drastically different from expectations based on what we thought we knew about the disease. The risk of death from Covid increases exponentially with age: more than half of all Covid deaths are over 80. Men are about 24 per cent more likely to die.

Yet more than half of long Covid sufferers are aged 49 or younger. Most are women.

The Omicron question

This brings us to Omicron. The variant has spread rapidly through millions of young people over the past four months, typically producing mild illness.

Yet there does not appear to be a strong link between the “mildness” of the initial infection and contracting long Covid. Of the 1.1 million people with symptoms more than a year after infection, just 75,000 were initially admitted to hospital.

Stephens started a podcast called *TLC Sessions* and has met hundreds of fellow sufferers. “Some had what was basically a cold at first. Others were asymptomatic initially,” she said.

Fortunately, progress is being made in the race to understand and treat it.

Patients are recovering, albeit slowly. Of the 1.1 million patients who reported long Covid in the past 12 months, 685,000 have had symptoms that last longer than a year.

McNelis, a former marathon runner, caught the virus in March 2020 and developed debilitating long Covid symptoms. “Whenever I had a shower and put shampoo in my hair, I’d have to have a standing rest before rinsing it out again,” said the 48-year-old.

There are many parallels between long Covid and ME, or chronic fatigue syndrome. Experts believe treatments for one could help the other.

McNelis decided to wear a heart monitor to keep his pulse below a certain threshold. “The theory from chronic fatigue syndrome is that if you overexert yourself, that can damage your recovery.” If all goes well, he will be running a half marathon in October.

Professor Betty Raman from Oxford University is leading pioneering research into the condition. She has been studying mitochondria, which power the body’s cells. “We see the mitochondria in people with long Covid aren’t as efficient at producing energy compared to people without it.” She is seeing whether AXA1125 — a combination of amino acids — is able to help restore the body’s metabolism.

Other treatments are being targeted at specific symptoms. One is insomnia, for which sleep therapies are being prescribed.

According to research by the Paracelsus Recovery clinic, one in three long Covid sufferers experiences mental health and addiction problems. Specialist mental health therapies are helping.

There is a huge demand for limited spaces at specialised long Covid NHS clinics. Of the 2,869 patients who had a post-Covid assessment in the four weeks to January 16, 34 per cent had been waiting at least 15 weeks. In the southeast of England, the proportion is 51 per cent.

Stephens recently saw a cardiologist for tests. Her heart rate, normally 54 beats per minute, often tops 94 just lying in bed. “The cardiologist told me, ‘The tests say your heart is fine but I have hundreds of people like you coming to see me every week. I have no way to help you — all I can recommend is that you go to a long Covid clinic’,” she said. Stephens is now on a lengthy waiting list.

Because Covid does not become “long” until 12 weeks after the initial infection, we are only just seeing the so-called “mild” Omicron wave — which saw more than 20 million people infected — filter through into long Covid.

The number of people with long Covid symptoms lasting more than 12 weeks jumped by 14 per cent between January and February.

Infection rates appear to be staying high: about one in 25 people have the virus, according to the ONS, a rise on the week before. Hospital admissions, having fallen for nearly two months, appear to be creeping upwards again — a reminder that the virus has not gone away.

Cause for optimism?

However, there is hope that long Covid may be less of a threat than it was. An analysis by the UK Health Security Agency found that [double-jabbed people were half as likely as the unjabbed to contract long Covid](#). High vaccination rates should mean Britain has much stronger protection against long Covid than a year ago. Yet Professor Danny Altmann of Imperial College London — one of the world’s leading long Covid experts — is worried.

“I’m aware of the support groups mentioning that membership is zooming up at the moment. It’s hard to know [whether it’s because of Omicron]. But it’s clear that there are still new long Covid cases coming online, even in a moderately well vaccinated country. That seems alarming.”

If long Covid cases do keep climbing, some fear that companies may not take its effects on the workforce seriously.

Andrew Gwynne, a Labour MP, has suffered long Covid for nearly two years. Instead of “bobbing” up and down to get the Speaker’s attention to ask a question or make a point in the House of Commons, last year he had to request permission to raise his hand instead: standing up was too exhausting.

He has been trying to persuade the government to take the issue seriously.

“The Department of Health and Social Care recognises the problem, but there’s a huge amount of work to be done with the Department of Work and Pensions,” he said. “I know people who are having to appeal their benefits decisions because they’ve had the work capability assessment on a ‘good day’ and have been deemed fit for work, when they’re really not.”

That may change with clearer definitions of the condition. Dr Ziyad Al-Aly, assistant professor of medicine at Washington University in St Louis, Missouri, has been studying the long-term effects of Covid on the heart.

“The term ‘long Covid’ was coined by patients, and that’s great — but we’re increasingly seeing it as a variety of different conditions under the same umbrella, just as you have more than 800 types of cancer,” Al-Aly said. “As our understanding evolves, we’ll get better at classifying it.”

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