

My long Covid: how I finally came back to life

Francesca Steele had given up hope. Then she tried an alternative health treatment



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GREY HUTTON FOR THE TIMES

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When I had been suffering from long Covid for nearly one year, a doctor told me: “It’s time for you to accept that you might never again be the same person you were before.” She said it so casually, as if it were no big deal.

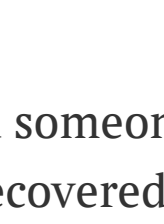

I didn’t want to believe her but I was at the point where I felt like my entire life was being stolen from me piece by piece. After getting a mild case of Covid at Christmas 2020, I then experienced a rollercoaster of symptoms including debilitating fatigue, stomach and muscle pain and a horrible, poisonous feeling similar to the flu.

I stopped meeting friends as I was usually too ill to go out. I stopped being strong enough to care for my children. Eventually I became housebound, barely able to walk beyond our front door. I stayed in for nearly four months. It was the worst time of my life. But fortunately for me, it wasn’t the end of the story.

I looked desperately for examples of other people getting better but despite there being two million long Covid sufferers in the UK, all I could see were stories of decline. I noticed that my symptoms seemed identical to those of many people with ME/CFS (sometimes called chronic fatigue syndrome or just ME), but found no solace there; the charity Action for ME says that about one in four ME sufferers remain severely ill for many years.

I was lucky that I had the resources to try other things. Indeed, overall I spent about £15,000 trying to get well. A private doctor put me on strong antihistamines, which have been shown to help some long Covid patients become less reactive to environmental triggers and food. We even hired a hyperbaric oxygen chamber and set it up in our bedroom. I would climb into it every day for an hour, hoping it might, as some claimed, help by boosting my cells’ oxygen distribution. And I paced meticulously. Pacing, recommended by the NHS, involves planning out your day in great detail so that you don’t exceed energy levels. But if anything, pacing made me worse.

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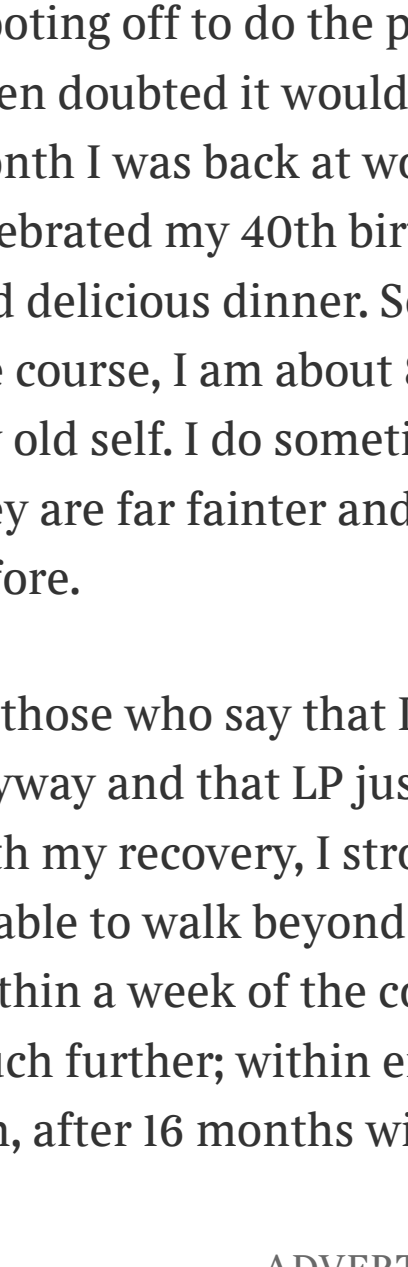
It was on a particularly bad day that I started to wonder about mind-body courses, which suggest you can control the reactions of your body by “retraining” your brain. I had come across people who had success with these courses while searching online. One that kept cropping up was called the Lightning Process (LP), a short brain-training programme that, enthusiasts said, also had an impact on the body.

Developed in the Nineties by the British osteopath Phil Parker, LP is a three-day seminar (which you can do in person or on Zoom, with a range of coaches you can find online) that combines neuro-linguistic programming with life coaching, hypnotherapy and osteopathy. Its goal is to give people tools to help themselves with a range of conditions, including post-viral fatigue syndromes, chronic pain and anxiety, by reducing the brain’s stress response. It claims to have helped 25,000 people around the world.

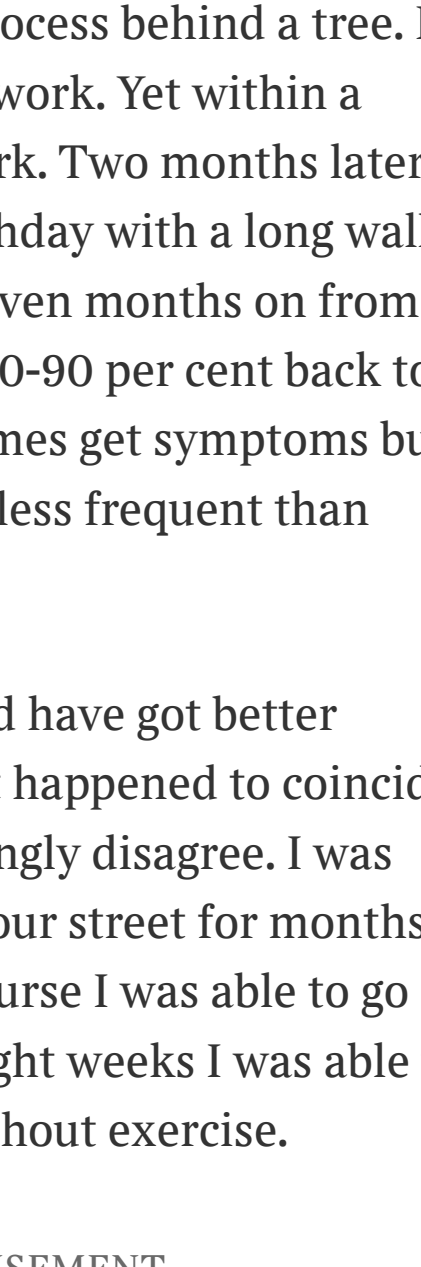
Whenever I found someone online who claimed to have recovered from post-viral fatigue conditions in this way I tried to track them down and speak to them directly to check they were real and not invented by snake oil salesmen. They weren’t. I spoke to a journalist who said the techniques had cured him entirely of ME. I spoke to a GP who had gone on to train as an LP practitioner after it helped her ten-year-old daughter to recover after three years. I chatted to several writers who said mind-body work had “cured” them of long Covid but they were afraid to speak out, something I understand because I was trolled after mentioning the concept on Twitter.

There is a sector of the ME community that lobbies hard against such strategies, suggesting that successes must be coincidental or made up. It’s understandable. Although there are an estimated 17 million ME sufferers worldwide, research funding has been minimal. Some patients become bedbound, unable to speak or eat. Some die. Yet reports persist of doctors trivialising the condition, suggesting it is “all in your head”. No wonder many in the ME community consider the promotion of mind-body work heretical. They believe that a biomedical solution hasn’t been found precisely because the condition has been labelled psychological. Since 2011, Nice (the National Institute for Health and Care Excellence) has also advised against the use of LP for ME, citing a “lack of clarity around the implementation of the process”, and specific concerns that people had been encouraged to “push through” their symptoms, which LP disputes.

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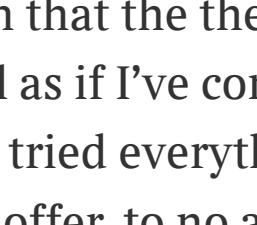
However, I kept hearing positive things about it on social media, and decided it was at least worth a shot. In March I did the course. The thinking is that a serious shock like a bad virus can send your body into permanent “fight or flight” mode and that your nervous system gets stuck sending messages of sickness that are no longer needed. Using the science of neuro-plasticity, which says that the brain adapts to the neural pathways used most often — and that in this case your brain has adapted to using neural pathways that prompt a sickness response — the course teaches you to “train your brain” to send different signals. So, instead of your immune system, your endocrine system and your inflammation responses all gearing up for an attack, they relax. Your hormones, your blood pressure, your heart rate, your thermoregulation and so on, all, in theory, return to normal. As Dr Anna Chellamuthu, a GP and LP practitioner, puts it: “The LP is absolutely not saying, ‘This is all in your head.’ This is a physical illness. It’s saying that physiology can change when you change your thoughts.”

During a £750, three-day Zoom course, our coach talked the three of us (all with long Covid) through various exercises and taught us all a routine to interrupt negative thoughts. Every time I had an anxious thought about symptoms, I had to say “Stop” and do an intense visualisation, imagining myself in a situation where I was energetic, healthy, confident.

It was not easy to stick to. Constantly interrupting your thoughts feels unnatural at first and there were times I was out at the park with my kids when I really didn’t feel like scooting off to do the process behind a tree. I often doubted it would work. Yet within a month I was back at work. Two months later I celebrated my 40th birthday with a long walk and delicious dinner. Seven months on from the course, I am about 80-90 per cent back to my old self. I do sometimes get symptoms but they are far fainter and less frequent than before.

To those who say that I’d have got better anyway and that LP just happened to coincide with my recovery, I strongly disagree. I was unable to walk beyond our street for months. Within a week of the course I was able to go much further; within eight weeks I was able to run, after 16 months without exercise.

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Various studies suggest the efficacy of mind-body work. In a recent pilot study conducted by a professor at Harvard Medical School, for example, all symptoms of patients with long Covid improved on a 13-week psychophysiological course. There is no doubt that more biomedical research is needed into post-viral fatigue conditions, and I, like others, hope that more evidence is found of the exact mechanisms at play. Dr Boon Lim, a consultant cardiologist at Imperial College Hospital who has treated many people with long Covid, says: “As medics we have been taught to focus all our attention on physical issues, to the detriment of patients. I think you need both physical and mind- body help to improve.”

I am also conscious that mind-body courses can be expensive. LP costs £750 (plus more for follow-up guidance). I found the intense nature of it uniquely motivating but cheaper mind-body work does exist, including the app Curable (I know one woman who recovered from 14 years of ME using it) and Suzy Bolt’s extremely compassionate, cheap (and some free) online classes.

For me, the process has been gradual, not immediate. I don’t claim that it will work for everyone or even that the theory is definitely correct, but I feel as if I’ve come back from the dead. Before it, I tried everything mainstream medicine had to offer, to no avail. Mind-body work has got me this far, and I believe it will get me the rest of the way. Without it, I believe I’d still be in bed, without hope.