

As they're told to exercise despite crippling fatigue, and advised they should banish 'negative thoughts'...

By **JEROME BURNE**

PROFESSOR Brendan Delaney developed a mild case of Covid just before the first lockdown in March, suffering the now-familiar symptoms of a cough, temperature and headache.

Feeling tired and achy, the 57-year-old London GP self-isolated for two weeks, by which time he had recovered enough to return to work.

But a week later, he suddenly experienced the 'most extreme fatigue'.

'I was breathless and had muscle pains and a recurring fever,' he says.

Professor Delaney, a specialist in medical informatics at Imperial College London, used to cycle 80 miles every Sunday, but after he developed long Covid — which is thought to have affected 60,000 people in the UK — even speaking to patients on the phone was a challenge. Sometimes he would feel better, but then he'd relapse.

Three months later, in June, when he'd been able to start working again (though only part-time), he still had brain fog.

The official treatment for lasting fatigue, which is now recommended to long Covid patients, is graded exercise therapy (GET). It involves doing a bit more exercise every day, with NHS website Your Covid Recovery suggesting: 'It is important that you start being active as soon as possible after discharge from hospital... You should aim to build up to 30 minutes of activity at least five days a week.'

For people exhausted by a simple phone call, this seems like a huge task.

This regimen has been prescribed for patients with the long-term fatigue condition known as ME (myalgic encephalomyelitis) or CFS (chronic fatigue syndrome) for nearly 20 years. However, when these patients complained they felt worse after exercise, they were told it was because they had a faulty belief that they couldn't exercise. As a result, GET was often combined with cognitive behavioural therapy to rid them of this mistaken idea.

The good news for these patients is that last November, treatment watchdog the National Institute for Health and Care Excellence (NICE), issued draft guidelines for ME which dropped the graded exercise approach from its recommendations — and replaced it with a treatment that is the exact opposite.

RATHER than issuing a prescription of what exactly they should be doing and pushing them to do more every day, patients are now being told to exercise only as much as feels comfortable, 'at a level that does not worsen... symptoms'. But while this sea change is welcome news for some, Covid patients with long-term fatigue are being told they need GET.

'The ME patients I knew through my practice howled with anguish at the idea of treating Covid patients with GET,' says Professor Delaney. 'I gave it a try as I'd told my ME patients in the past to do. But as a result, my fever came back and I felt a lot worse.'

Professor Paul Garner, another long Covid sufferer, described his experience in The BMJ in May as 'being on a rollercoaster of ill health' after developing the illness in mid-March. He is a senior member of the Cochrane Collaboration, a respected source of information about the latest treatments and evidence.

He was shocked, however, when he consulted its database about treatment for long-term fatigue.

'It told me I needed cognitive behavioural therapy to challenge "unhelpful negative thoughts",' he told Good Health. 'This was shortly after I had suffered a three-day relapse following a ten-minute bicycle ride. That wasn't the result of negative thoughts.'

By July, a growing number of doctors with long Covid, including



Shocked: Long Covid patient Professor Brendan Delaney

Pictures: ISTOCKPHOTO / GETTY / RICHARD CANNON

No wonder doctors think their long Covid treatment is misguided

Professor Delaney and Professor Garner, had formed online support groups where they described their experiences and discussed alternative treatments. Professor Garner says those in his support group each benefited from going at their own pace, even though they had different symptoms.

Professor Delaney was shocked at the response of doctors treating him and others for fatigue with the approved protocol. 'There was complete disbelief when we weren't getting better,' he says.

'They were pretty unsympathetic and negative. We realised this was what ME and CFS patients had been suffering because of the graded exercise therapy advice.'

Patient activists had been warning that GET was 'ineffective and could be deeply damaging to patients since 2007, when the previous guidelines came out', says Andy Devereux-Cooke, co-founder of online group Science For ME.

What patient surveys have repeatedly found is that 'pacing' — where they exercise within their

comfort levels — is much more helpful. One survey of more than 1,400 patients, published in the Journal of Health Psychology in 2017, found that 44 per cent reported an improvement in symptoms when 'pacing' while exercising, compared with 12 per cent for GET.

The patient groups argued that their symptoms, such as profound fatigue, poor memory and irregular changes in blood pressure, all suggested a physical cause.

As Andy Devereux-Cooke

explains: 'It eventually got enough academic support for patient advocates like me to be invited to be part of the committee that draws up the NICE guidelines.'

The committee commented that the guidelines should end the 'stigmatisation and prejudice' patients had suffered as a result of their fatigue being described as 'psychological'.

The NICE experts accepted the claim that profound fatigue was the result of a disordered energy metabolism and that patients should stay in their 'energy envelope' — the new term used in the draft guidelines, which is essentially pacing.

EVEN though the new guidelines are specific to ME and CFS, the gentler approach to treating chronic fatigue has been receiving strong support from doctors who have fallen victim to long Covid.

The hope is that their involvement could help transform our understanding of what's going on with ME and long Covid.

Already, multi-disciplinary clinics are being set up to properly address all long Covid symptoms. One of the organisers is Dr Ian Frayling, a senior clinical research fellow and pathologist at Cardiff University, who has long Covid himself.

'The aim is to make treatment more specific and targeted and find out more about the biological causes,' he told Good Health.

There are plenty of possibilities to explore. Research by a Norwegian team, published in JCI Insight in 2016, found that some cells in patients with CFS/ME were less efficient at making energy compared with healthy people, and they produced excessive amounts of waste products when the patients did exercise. Less oxygen was being carried in their blood and less blood was getting to the brain and heart.

It's possible this may be happening with long Covid, too, says Dr David Strain, a senior clinical lecturer at the University of Exeter Medical School.

'The similarity between the symptoms of fatigue in Covid and CFS/ME suggests a common factor,' he says.

'There is evidence both have blockages in the tiny blood vessels that supply our cells with nutrients and remove waste.'

'This could explain symptoms such as brain fog, crippling tiredness and inability to exercise.'

But it is still early days, he stresses. And this won't help long Covid patients currently being advised to push the exercise envelope.

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THIS week: Cooked potatoes and pasta
COOLING potatoes and pasta in the fridge after cooking increases the levels of resistant starch — starch that cannot be easily broken down in the small intestine.

This makes them 'filling', but 'with about half the available calories of other starchy foods', says Daniel Commane, a



senior lecturer in Nutritional Sciences at Northumbria University.

'Eating food rich in resistant starch is also associated with more even post-meal blood sugar control.'

'In addition, most resistant starch passes undigested to the colon, where it has a prebiotic effect, increasing the growth of friendly bacteria.'