

Paul Garner: Covid-19 at 14 weeks—phantom speed cameras, unknown limits, and harsh penalties

“If my husband had said he was still sick with covid-19 after a month, I’d say he was milking it.” Straight talking from a Liverpoolian woman on one of my WhatsApp groups in April when I had been ill for a month; what would she say to me now at 95 days? I am unable to be out of bed for more than three hours at a stretch, my arms and legs are permanently fizzing as if injected with Szechuan peppercorns, I have ringing in the ears, intermittent brain fog, palpitations, and dramatic mood swings. Am I milking it? Is the virus still there? Or do I have CFS/ME?

I am cautious about labelling conditions, particularly with a new virus that has many different effects on our bodies. I tried to avoid the term “post-viral fatigue” in an earlier article as fatigue was there from day 1, and I was concerned the term could lead to people underestimating other covid related symptoms indicating life-threatening effects. Now, at week 14, my symptoms have progressed. The waves of mind boggling headaches and severe prostration have ebbed. An excellent hospital consultant examined me. “Post-viral fatigue”, he said. “You don’t need an echocardiogram or CT scan. I recommend rest and pace.”

I committed to rest in my last article, but let me tell you, pacing is not easy. I held two opposite ideas in my head: the need to convalesce, and that I could truncate the recovery by pushing my limits. But it was as if I was being followed by phantom speed cameras. You don’t know the speed limit and you don’t know when the penalties will arrive. You find out that when they do they are harsh, stopping you in your tracks for days. I have had to reframe my life practically, psychologically, and spiritually. I thank Anna, a friend who is a physiotherapist specialising in rehabilitation, who helped me learn.

Anna explained that the “busts” can be experienced as a reprint of their entire symptom complex in the acute phase. I had fatigue, headaches and tingling nerves as my main symptom, and that’s what comes back when I overdo it. For a neighbour, who pushed herself to get a contract in to secure her salary, her collapse manifested as severe abdominal pain, diarrhoea, and a sore throat: a complete re-enactment of her initial illness. I learnt that in convalescence after a severe assault, the body goes into protect mode, so if it isn’t getting space to recover, it shuts you down by bringing an embodied memory of the illness.

Once I recognised this pattern, some of the angst among the thousands of “long haulers” on Facebook is explained. Some clearly have symptoms that need investigation and management, and troubling late manifestations of the disease; but for others the return of symptoms, that may include shortness of breath, sore throat, this could be a manifestation of post-viral syndromes. I suspect people recovering at home and their doctors may not recognise this, and thus do not realise it may be exertion—both mental and physical—that is causing their symptoms to return. Without instituting careful pacing, people suffer, and their recovery is delayed.

What is worse is that there is increasing evidence that some doctors are dismissing this illness. People write, "I am desperate! My doctor says I have anxiety, but I know this stuff is real". Health services are largely institutionally prejudiced against people with chronic fatigue and ME, and in some cases these attitudes are framing the service response to covid-19. Yet for us "long haulers" the symptoms are the same, the management schedules are the same, even if we don't quite fit the somewhat arbitrary definition of "chronic" at 4 months.

A post-viral tsunami is hitting our health services right now, yet in the UK it doesn't even seem to be on the national agenda. NICE have issued 28 rapid reviews and guidance on covid-19 this year, but their guidance on the chronic fatigue syndrome/myalgic encephalomyelitis is 13 years old. There is little evidence in the UK of a co-ordinated response, that is truly multidisciplinary, involves organizations such as the ME Association, and includes patients.

Society is acknowledging the "long haulers" but part of the picture is missing. What about people less privileged than us articulate middle classes mobilising ourselves, writing to MPs, and talking to journalists? What about the minority groups, the single parent households, people on zero hours contracts, where long convalescence is not an option? These people are trying to navigate an illness that bites back like a demon if you overdo it, batters you physically and mentally, and leads you to doubt your own sanity. Pushing themselves because they have no choice will lead to further illness, suffering, and distress. They are being left behind.

This stuff is real. People are ill. Doctors need to stop diagnosing this as anxiety. We have messed up before, lets' not do it again with long term covid-19 illness.

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Competing interests: None declared

I thank Anna Bulley, specialist physiotherapist (rehabilitation and chronic conditions), for her help in my rehabilitation, pacing and teaching me about post-viral illness.