

Mr Pankaj Jain, one of those seeking the information, was asked to provide a letter to the college stating that he had no intention of harming the reputation of the college. Submission of the letter failed to elicit any response. When pressure was brought on the administration, the answers elicited command admiration.

‘First they said the documents have been seized by CBI, then they said the clerk who was handling it has been arrested by CBI, and then they said the clerk who was handling it committed suicide inside the room where the documents were kept. The room is now haunted by his ghost and they are scared of opening the locks.’

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SUNIL K. PANDYA

Letter from London

It is almost two years since we first heard the whisperings of a coronavirus causing concern among public health experts. As the story began to attract media attention and the implications became more visible, people in the UK responded in different ways and at different speeds depending on their circumstances. Among disabled people, many of us began to take precautions early on. A lot of people took the decision to shield from the virus before advised to do so by a government more concerned with keeping pubs open than confronting the reality of Covid-19 and the devastation it was already wreaking in Italy and elsewhere.

We know only too well by now that the pandemic has exacerbated pre-existing social inequalities. This cannot have come as a surprise to anyone other than the most privileged people living in ignorance of the structural oppression that governs the lives of so many of their fellow citizens. For disabled people, it was all too predictable. Demonised by successive governments as either scroungers or frauds, the lesser value placed on our lives has been illuminated to frightening effect during the pandemic. For almost two years the narrative in UK has been that most people who die from Covid are either old (so their time was up anyway, goes the implicit assumption) and/or they have other underlying health conditions which make them more vulnerable (proving that Covid is not a serious threat to ‘normal’ people and therefore the measures taken to curb the pandemic are unjustified). We have seen this play out through the government’s disregard for accessible communication with disabled people, a failure to protect services that disabled people rely on for survival, the imposition of ‘do not resuscitate’ orders without consent, and the failure to prioritize huge numbers of disabled people for vaccination despite all the evidence showing that we are at greater risk if we catch the virus.

Poor people, black people, women—all have experienced the exacerbation of discrimination during the pandemic, and where these identities intersect, even more so. Yet there is a particular

irony to the government’s disregard for disabled people during this pandemic, which lies in the fact that Covid-19 has already created so many more of us. There is palpable global relief that the Omicron variant has proved less severe than feared. But any strain of this virus remains a potent threat. Because while you may not be hospitalized, that does not guarantee that you will fully recover. This is something that those of us who have lived with post-viral diseases for years and decades know only too well. We also know the hostility and disbelief that people with post-viral illness are all too often met with from the medical profession, the media and wider society.

The term ‘Long Covid’ was coined early in the pandemic, as growing numbers of people who got sick during the first wave did not recover. Not recovering does not mean being left with a vague malaise; it means debilitating symptoms that profoundly impair a person’s quality of life, in some cases transforming it beyond recognition. That is hard enough to manage, but what can be harder for many people—and I speak from experience here—is seeking help from a doctor only to be dismissed as an over-anxious example of ‘the worried well’. Those who persist have historically been offered cognitive behavioural therapy (CBT) and graded exercise therapy (GET). CBT can support people to manage the experience of chronic illness (it is not a treatment), while GET has been repeatedly shown to actively exacerbate symptoms and has left many people far worse than when they began. For those of us with ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome), seeing people with Long Covid confronting systemic disbelief, invalidation and harmful treatment is troubling to say the least.

Is there any cause for hope here? For those newly ill, that might sound insensitive. But for those of us with longer experience the emergence of Long Covid brings a glimmer of hope for research funding due to its occurrence on a global scale that makes it hard to ignore. There is also evidence from media outlets of increased interest in just how devastating post-viral illness can be, which leads in turn to greater public awareness. And as our numbers swell, research funders are finally showing more interest after the shameful historical neglect of ME/CFS

(which predominantly affects women and attracts less research funding in the USA than male pattern balding).

More scientists being funded to study Long Covid should bring breakthroughs for everyone. Which leads to a final point, which is both a cause for hope and concern, and that is solidarity among patients and allies. Attracting finite attention and funding risks competition among patient groups who are living through similar experiences—both in terms of symptoms and the inadequate response of doctors not trained to take post-viral illness seriously. The ME/CFS community had an enormous and long-awaited breakthrough in 2021, with the NICE (National

Institute for Health and Care Excellence) treatment guidelines revised to instruct against prescribing GET and to reframe CBT as a management tool not a treatment. This should also benefit people with Long Covid, with whom we share so many symptoms. We must not compete, but rather join together and approach this new era in a spirit of solidarity, seeking improved care and services that will benefit everyone. The pandemic has shown that our government does not care about disabled people. In times like these, we must advocate for each other in the interest of us all.

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