

Response to the proposed psychologisation of treatment in ongoing covid patients by ongoing covid patient groups

Wednesday, October 21st, 2020

We, the hundreds of thousands of long Covid sufferers, are deeply concerned about the treatment being proposed for Chronic Long Covid patients. Together, we have suffered for more than 6 months, experiencing over 200 symptoms between us, with an average of around 50 per person. Our lives have been shattered by Covid-19 and the post viral illness that has followed. We have waited months for clinics and treatment and now we are deeply concerned to hear from a NICE ME/CFS Guideline Committee member (via twitter) and other Committee members (via publications) which propose and support CBT/GET therapies for Long Covid. The recent NIHR publication also states that the intention is to treat long Covid sufferers (ventilated) with biopsychosocial therapies instead of ruling out a biomedical cause for our illness.

This has been the case for ME patients here in the UK for decades and the therapies used, graded exercise therapy (GET) and cognitive behavioural therapy (CBT), have caused many of them great harm. The USA has removed such therapies and recently NICE here in the UK has advised against using them. Thus, we cannot understand why then, both the NIHR, NICE and others are pursuing this outdated clinical advice? It is even more concerning that back in July, NICE clearly stated that it wouldn't be recommending it, so why has it changed?

Moreover, the validity, reliability and integrity of the findings of the PACE trial on the Deconditioning/CBT/GET model have been highly questionable. This is especially the case since they were based on research where 13% of participants already met a key outcome of threshold at baseline. Moreover, the recovery threshold was dropped to below that of heart failure so that even those who deteriorated were classed as "recovered". The PACE trial in fact proved that CBT and GET did not provide sustained improvement in ME myalgic encephalomyelitis (or encephalopathy).

We quote a few of the leading papers on its validity here (albeit, this is not an exhaustive list). Professionals questioning it's validity include global public health specialists, professors of psychology and many others in academia as well as MP's, leading newspapers like the Times and other journalists. Some of the UK's and World's top infectious disease experts are amongst them as well as numerous patient advocacy groups.

The PACE trials published in the Lancet in 2011 have drawn much criticism:

- *Professor Racaniello, June 2020, highlights the indisputable methodological and ethical failings of PACE.*
- *The PACE trial was deemed to be so poor that it is held up as an example in teaching institutions in the US of how scientific trials **should not** be conducted.*

- *Surveys of the ME population reveal that at least 50% of the patient population report being harmed by the protocols recommended by PACE. It's sister trial, The FINE trial, also failed to show any positive benefit in following the same recommendations.*
- *Since the Pace Trial, many experts here in the UK and USA signed a petition addressed to the Lancet calling for the removal of this dangerous therapy.*
- *Many academic papers have since also called for it's removal.*

The similarities between ME, a disease which often has a post-viral onset, and long Covid must be noted. Indeed, many long covid patients have already been diagnosed with ME/CFS or are showing classic ME diagnoses like mitral valve prolapse, myocarditis and fatigue. These patients have been diagnosed by many physicians, including some of the UK's foremost ME experts. Indeed, many leading ME consultants are now stating that Post Covid is identical to ME. Furthermore, when comparing ME and Post Covid (chronic long covid) the most important similarity is that chronic long covid has the hallmark symptom that warrants a diagnosis of ME: that of Post Exertion Malaise.

It is of note that both CBT and GET are now deemed to be both irrelevant and could be harmful to ME patients and hence, Long Covid ones too. Indeed, the authorities in the USA have entirely removed them from Physician/GP guidelines for ME patients. Why then, is it being put forward for Long Covid patients (including those ventilated or not)? It is deeply troubling!

We are very concerned to hear that having our physiological symptoms will be treated with inappropriate, dangerous biosocial psychiatric therapies. The Chronic Long Covid support group have catalogued almost 200 effects, almost entirely physiological over the last 6 months, even for those with non-organ involvement. We are not prepared to accept this as a treatment when we have already seen patients suffer heart attacks and breathing problems from it as it has been prescribed by GP's and others who have failed to rule out other causes/effects.

Moreover, in a recently released statement, NICE said that it was aware of concerns related to the impact of graded exercise therapy (GET) for managing post-viral fatigue in patients recovering from Covid-19. It noted that its current advice on managing fatigue in ME/CFS patients may not be appropriate for this group of patients and acknowledged that it could also be out of date for other groups. This is more so since ongoing long covid patients have not yet been treated or had other causes ruled out. Therefore, it is deeply troubling to find that health professionals are recommending these treatments for people suffering from Long Covid.

Anxiety or stress has been consequential: caused by the lack of medical support, by not being taken seriously, and by being abandoned up until now and largely ignored both by the NHS and the Government. **We are not plagued by psychological problems, nor are we able to overcome our primary physiological illness with it.** Whilst we welcome the establishment of clinics in response to ongoing chronic long covid, sending us to psychiatrists is unacceptable when medical causes for our illnesses have not been actively investigated and ruled out.

Likewise, we feel it is within our human rights, our patient rights according to the Hippocrates Oath and on the basis that GET/CBT is based on failed research, not a therapy we can trust nor want to engage in.

We want an assurance from NIHR, NICE, the Rt Hon Secretary of State Matt Hancock and NHS England/Scotland/Wales/Northern Ireland that the **post-Covid clinics will be set up to treat our multi-system illness**, that the process will be transparent and will include all patient voices, including the ME Community who have much expertise in this field (50 years plus). These clinics/Your Covid Recovery portal should not be headed by psychiatrists or psychologists. Unless we are able to incorporate the experiences of Long Covid and ME patients then these clinics are likely to replicate the harm already being experienced by ME patients in the UK and beyond. People with Chronic and other Long Covid illnesses as well as other secondary illnesses, deserve better. We need scans of our organs which so far have largely been provided by private research teams which means that very few of us have had them. Those with no proof of having had covid, which is the majority of us, have been hung out to dry. Clinicians need to check our physiological symptoms for damage, run tests and carry out scans.

We stand united against this psychologisation of our very physical illness.

Signed

‘The Ongoing Covid Patient Voice Collective’

A collective of patient support & advocacy groups experiencing all effects of post viral illness from ongoing Covid 19.

The Covid 19 Connected Group

The Chronic Long Covid Group

The Coronavirus-Survivors Group-Covid 19

Positive path of wellness (Covid UK Longhaulers Group)

Ladies Fighting Covid (50+ days)

The Covid 19 Support group for Survivors & their families

The Corecovered Community Group