CHRONIC FATIGUE SYNDROME AND LONG COVID

Charities, patients, and researchers are working together to find the cause and effective treatments for ME/CFS

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As a charity that funds biomedical research into myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), we are not aware of any researchers who hold negative views about the patient community.

Patients, charities, and researchers are all working together on research initiatives such as Decode ME (https://www.decodeme.org.uk), the ME Biobank (https://cureme.lshtm.ac.uk/the-uk-mecs-biobank), and cardiorespiratory exercise testing.

People with ME/CFS feel let down by the medical establishment because almost all biomedical research until recently has been funded by the charity sector. Almost all government funding has gone into research based on a flawed psychosocial model of causation involving abnormal beliefs and behaviours and deconditioning. This research resulted in the current NICE guideline recommendations, published in 2007, for cognitive behavioural therapy (CBT) and graded exercise therapy (GET).

Having reviewed clinical trial and patient evidence for these interventions, NICE now states in the introduction to the draft of its updated guideline on ME/CFS that "because of the harms reported by people with ME/CFS, as well as the committee’s own experience of the effects when people exceed their energy limits, the draft guideline says that any programme based on fixed incremental increases in physical activity or exercise, for example graded exercise therapy (GET), should not be offered for the treatment of ME/CFS." It also emphasises that CBT is not a treatment or cure for ME/CFS.

People with ME/CFS who have not been listened to by health professionals and told that their symptoms are "all in the mind" deserve an apology. This attitude has meant that biomedical research into the underlying cause of ME/CFS has not taken place at the speed it should.

NICE has warned that current recommendations regarding GET for ME/CFS are not appropriate for people with long covid. This new cohort of patients with post-viral illness should not have to suffer the same mistakes that have been inflicted on people with ME/CFS.

Competing interests: None declared.

Full response at: https://www.bmj.com/content/373/bmj.n1559/rr-12


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