# **Why ME/CFS is still so poorly researched and treated**

Readers respond to George Monbiot’s article on the treatment and attitude of the medical profession to the debilitating condition

I am writing to express my appreciation of George Monbiot’s perceptive article ([‘You don’t want to get better’: the outdated treatment of ME/CFS patients is a national scandal, 12 March](https://www.theguardian.com/commentisfree/2024/mar/12/chronic-fatigue-syndrome-me-treatments-social-services)). I have lived with severe fatigue for more than three years, following a mild Covid infection. It is difficult to describe what it is like and it is not surprising that it is not well understood. My experience is that it is necessary to overcome my instincts to push myself, since running out of energy results in even more limited stamina over weeks or months.

It must appear to others that I am neither constantly exhausted nor pushing myself. But if I give in to the instinct to do more, I push myself back into a state of self-perpetuating exhaustion, where my expectation of what I can manage lags behind my declining stamina.

I cannot measure how much energy I have used, particularly cognitively. And I can’t measure how exhausted I am without reaching a state where actions such as reading or talking become difficult, a state from which it is hard to recover. All waking time is using energy, and any overexertion may have consequences days into the future, making it unclear as to cause and effect.

NHS help has been limited to advice on pacing myself. I had a work capability assessment for universal credit and was struggling to speak by the end of a 40-minute phonecall. I was astounded when I was found to be fit for work. I was able to have this finding overturned by tribunal, but the experience was distressing and sapped my energy for months.

I expect a physiological cause and treatment will be found eventually, but in the meantime our health and welfare systems need to be updated to support those living with chronic fatigue.
**Ewen Tanner***Yeaveley, Derbyshire*

As the mother of a 33-year-old woman who has had ME/CFS since contracting a virus at 15, the attitudes of the medical profession in this article were all too evident in our experience. Back then, I was being told to “get her into school” – it made her 10 times worse. As little as five years ago, she was being pushed down the route of “exercise and psychological solutions” by the hospital – a box-ticking exercise. When the pandemic hit, the first thing we said to each other was that there would be a huge increase in ME/CFS. There has been, but it’s called long Covid. It’s our fervent hope that the research taking place will also look at ME/CFS and help the thousands of people who have had their lived blighted by this misunderstood condition.
**Name and address supplied**

As a ME/CFS patient who has recovered, I agree with every word of George Monbiot’s article. But he has omitted the next step after a correct diagnosis: effective treatment. I recovered by taking sertraline (an antidepressant) as part of a small 1990 trial at the Royal Free hospital in London. Our mental states were assessed as we entered the trial; none of us was depressed. Nobody knew why sertraline worked. Later, it was found that ME patients cannot get deep sleep, but sertraline gave them back that sleep. No other trials of sertraline seem to have taken place, presumably because of the medical establishment’s attitude.
**Cynthia Floud***Haddenham, Buckinghamshire*

George Monbiot has written an excellent critique of why the medical profession is still failing to provide proper care for people with ME/CFS. Although we now have a [new guideline](https://www.nice.org.uk/guidance/ng206) from the National Institute for Health and Care Excellence (Nice) that recognises ME/CFS is a genuine and disabling condition, there has been disappointing progress in implementing the key recommendations.

Nice recommends that a diagnosis should be made at three months from the onset of symptoms. But many people are waiting a year or more for a diagnosis. Very few existing specialist referral services are able to offer the type of multidisciplinary care that Nice recommends, and services for the 25% of people who are severely affected are not being prioritised.

Access to specialist care in England remains patchy and is nonexistent in Scotland, Wales and Northern Ireland. Children with ME/CFS are still being threatened with inappropriate childcare proceedings. For a condition that costs the country about [£3.5bn a year](https://www.openaccessgovernment.org/understanding-impact-myalgic-encephalomyelitis-chronic-fatigue-syndrome/174788/) and affects at least 250,000 people, government investment in research and management has been pitiful. This neglect, which has been based on what is now discredited science, can no longer continue.
**Dr Charles Shepherd***Honorary medical adviser, ME Association*

I was depressed but not surprised by the article. I worked as a GP for 34 years until retiring and looked after a number of patients with CFS. Several had switched to my list because their previous GP felt their symptoms were purely psychological. I felt that they had significant physical symptoms of fatigue that affected their health, as well as a psychological reaction to the impact of this on their daily life. They often gave a clear history of having been under a period of prolonged prior stress, then catching an unpleasant virus infection, particularly glandular fever, and failing to recover.

One of the few good things that has come out of the pandemic is that there is increased awareness that a viral infection can lead to long Covid, the symptoms of which are very similar to CFS. There is now research happening into long Covid and I sincerely hope it can also help people with CFS.
**Dr Ros Kennedy***Bristol*

As people who have recovered from chronic fatigue conditions ([ME in one case](https://www.livingproof.org.uk/mecfs) and [long Covid in the other](https://www.theguardian.com/commentisfree/2021/jun/10/long-covid-hope-recovery-symptoms)), we share George Monbiot’s frustration. Yet he demonstrates his own lack of understanding by lashing out at a school of thought supported by scientists who believe the condition is a complex interplay between the biological and psychological.

The target of most of his ire is the claim that, for some patients, the physiological response can become dysfunctional and fear, including the belief that they will never recover, fuels this vicious cycle. [The interplay between the brain, beliefs, perception and hormonal and neuronal changes](https://www.tandfonline.com/doi/full/10.1080/02813432.2023.2235609) influences many bodily functions, and can account for the debilitating symptoms. We need scientists to keep researching these conditions. An appreciation that this biological illness can be influenced by unconscious expectations can help patients like us to get the right help, which includes appropriate psychological strategies.
**Fiona Symington** *Oxford***Paul Garner** *Professor emeritus in infectious diseases, Liverpool School of Tropical Medicine*

George Monbiot appears to confuse the doctor paying attention to a patient’s fears and emotions with dismissing their illness as somehow “unreal”. I suggest such a view is ill-informed and likely to be unhelpful for patients with any illness.