

ME - what's the problem?

This is an "invisible illness". People with ME, severe or moderate, disappear from public and professional view, and apparently from the public conscience. Life for those with severe ME is terrible: there are few conditions where patients suffer so much for so very many years, where the medical profession in general has so little involvement. Watch "Voices from the Shadows" if you want to see the reality of their lives.

"No other set of patients had ever measured so poorly. CFS patients experienced greater "functional severity" than the studied patients with heart disease, virtually all types of cancer, and all other chronic illnesses." – Dr. Peterson's Medical Outcome Study

"My H.I.V. patients for the most part are hale and hearty thanks to three decades of intense and excellent research and billions of dollars invested. Many of my C.F.S. patients, on the other hand, are terribly ill and unable to work or participate in the care of their families. I split my clinical time between the two illnesses, and I can tell you if I had to choose between the two illnesses I would rather have H.I.V. "

– Dr Nancy Klimas, in 2009,

Over the last 40 years the total amount of money spent worldwide on research into ME is roughly one month's current spending on HIV/AIDS research, and only a quarter of that has been on biomedical research. One week's money! What progress do you expect from that?

In the UK, MPs have put pressure on the Medical Research Council three times to improve things: the Chief Medical Officer's Report of 2002, the Gibson Inquiry of 2006, and the Early Day Motion of 2010. In each case the MRC set up, reorganized or renamed a committee to look into it. Sixteen years later the progress has been minimal. In response to the EDM, the MRC announced that it had set aside £1.6 million for biomedical research, and funded 5 studies. We thought that was a first step. Actually, apart from one follow-up study, that was it.

The NHS, via its National Institute of Health Research, has a similar amount to spend on research as the MRC. Until very recently it had not funded a single biomedical study on ME (the amount spent remains tiny).

The UK charity, Invest in ME, is setting up a centre of excellence for examination and research in the Norwich Research Park. The UK ME/CFS Biobank, set up by 3 charities and currently managed by the ME Association, has actually had \$2.1 million funding from America. The MRC and the NIHR have no involvement in either.

The prevailing view in the UK remains that patients with ME can be treated, or even recover, with cognitive behaviour therapy (CBT) and graded exercise therapy (GET). The only evidence put forward to support this claim comes from studies that rely entirely on patients' answers to questionnaires. Objective measures, such as walking tests, step tests, activity monitors, or return to employment, show no improvement. American government health agencies reject these studies, and no longer recommend CBT and GET as treatment for ME.

However, this view is so entrenched that it dominates how patients are viewed by their healthcare workers and for employment, employment benefits and health insurance. Parents of children with ME see how much their children suffer from graded exercise and enforced school attendance. But when they intervene to stop these interventions, they are often referred to social services and face child protection investigations.

We know there is no evidence that CBT cures or even treats ME: now we need to spread the message. We urgently need substantial funds to support thorough and rigorous biomedical research into ME, especially to address the needs of the severely affected patients who are simply hidden from view. And for that we need your help.

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