

ROYAL SOCIETY OF MEDICINE

ME/CFS: Frontiers in research, clinical practice and perception.

THE POLITICS OF ME/CFS.

Ladies and gentlemen, I am grateful to the Royal Society of Medicine who have given me the opportunity to offer a political view of ME/CFS.

I will have been an Independent Crossbench member of the House of Lords for forty years in the autumn. For more than twenty of those years, with the help of a great many other people in the community, I have been trying to persuade governments of different colours that ME/CFS, together with organophosphate sheep dip poisoning, Gulf War Illnesses, Aerotoxic syndrome and other medically unexplained physical symptoms, known as MUPS, are not figments of patients' imaginations, nor are they placebo effects, but are very real conditions.

In so far as ME/CFS is concerned I have had some support from Members of Parliament who have constituents with the illness, but have been ploughing rather a long and lonely furrow in the Lords. For the sake of brevity, I will call the condition ME, which is what most patients prefer, except where accuracy demands otherwise. I know that the medical profession uses the shortcut term CFS, but that covers a much wider range of conditions than what I know of as classic ME. I have to say that I do deal with what are probably the worst cases.

I came to ME through parents who had used OP head louse shampoos on their children – treatments recommended by doctors and school nurses. Some children developed symptoms which were labelled ME within months of the treatment. I don't know whether you recall that the advice was to shampoo the child's head and, without rinsing, cover the head with a shower cap and leave overnight, to be rinsed off in the morning. Anyone with any knowledge of OPs knows that one of the most absorbent parts of the body is the scalp, and that some individuals are more genetically susceptible than others; so these poor children were poisoned.

Very unfortunately, once a person, be they child or adult, has the ME label all support and assistance from the medical profession and social services seem to vanish into thin air. Despite the World Health Organisation classification of CFS/ME as a neurological condition under ICD 10 G93.3 and this classification being accepted by Ministers of both the Department of Health and the Department for Work and Pensions; despite major reports, one by the Chief Medical Officers working group on CFS/ME in 2002 and two others by the All Party Parliamentary Group on ME in 2006 and 2010, all of which recognise the severe impact that this disease can have on many patients' lives, far too many of those professionals treating and caring for people with ME have not received the message. The CMO Report mentions that "The disbelief and controversy over CFS/ME that exists within the professions has done nothing to dispel

public disbelief in the existence of such a seemingly varied and inconsistent illness.” Despite all the fine words of Ministers and report writers, I repeatedly ask myself why it is that the recognition and treatment of this illness has remained in the doldrums for so long.

All Party Parliamentary Groups are supposed to be for the enlightenment of Members of Parliament from both Houses. The purpose of the APPG for ME is to: “Raise awareness of ME and support the improvement of health, social care, education and employment opportunities for people affected by ME.” There was a problem with communicating with Ministers effectively at what turned out to be large public meetings with few MPs present. After consultation with the leaders of the main ME charities and support groups, Forward-ME was formed in 2008 under my chairmanship. We have met successfully with people such as Steven Holgate, Lord Freud, Edward Timpson MP and ATOS as well as others in the health, social care and education world and are, I believe, respected for the respect that we show to each other and to our speakers. The APPG was re-formed in 2010 on these same principles and we now work together very happily, though meetings are still attended by very few MPs.

When we think of politics we tend to think of party politics – what goes on in the Westminster village, in local government or at the parish pump. It was a while before I recognised that amongst other settings there are medical politics. Until the 1980s, when the Press picked up on the ‘Yuppie flu’ diagnosis, there

seems to have been tacit acceptance that ME was a real physical condition even though the cause was then, as it is now, unknown. There were a number of notable British doctors, amongst them Dr A Melvin Ramsay, who flew the flag for Myalgic Encephalomyelitis from the 1950s onwards, Dr Elizabeth Dowsett, Dr Alan Franklin and Dr John Richardson who, from their observations of ME patients over decades, were convinced that ME was caused by persistent viral infections. This persistence would appear to be confirmed by Dr Mady Hornig and Dr Ian Lipkin at the Centre for Infection and Immunity at Columbia University's Mailman School of Public Health in their 27 February 2015 paper – 'Immune Signatures in Blood Point to Distinct Disease Stages, Open Door to Better Diagnosis and Treatment', who have identified distinct immune changes in patients, said to represent the first robust physical evidence the ME/CFS is a biological illness as opposed to a psychological disorder., though I readily acknowledge that we still have a long way to go.

It was when a small group of psychiatrists from the UK, Europe and the USA purloined ME and renamed it CFS in the mid-1980s that the real problems began. They insisted that it was a psychosocial behavioural problem that could be readily overcome with a course of cognitive behavioural therapy and graded exercise. From their earliest beginnings, they managed to attract the attention of the media and of their medical colleagues with their assertions. They found their way onto government advisory committees and research organisations; onto the

boards of medical publications and into insurance companies where their message was greeted with apparent delight because these organisations would not have to think any more. The cause and solution were at hand. No need for doctors to do too many investigations; no need to perform anything but psychological research; no need for social security payments by finding that claimants are really fit for work. They developed a means of stifling opposition by refusing to publish papers showing biological causation and, joy of joys for the insurance companies found that patients were reporting a psychological condition which was excluded in their policies. As recently as last year CFS was described as ‘a culturally driven disorder with no known organic cause’ in the BMJ.

This school of psychiatrists has persisted in their view despite more than 6,000 peer reviewed papers, including experimental studies which demonstrate a range of biological findings associated with people with ME. Funding for biological causes and treatments is miniscule against the funding for psychiatric or psychological ones. Researchers such as those funded by Invest in ME and ME Research UK, have funded excellent pilot and seed corn studies on a shoestring, while a significant number of biomedical research applications have not been funded by the MRC in the past 20 years, including some targeted at pathophysiology. It is hard to believe that all were written so badly that they could be rejected, particularly as some came from established researchers with a

track record in this and other fields. Could it be that the expert reviewers were, once again, psychiatrists who appeared to have an interest in suppressing research that counters their views? Many suspect this to be the case. This can only be political. It is also political suicide for researchers in major universities to suggest that they conduct studies into biological causes for ME.

The largest and most expensive state-sponsored treatment studies (the PACE and FINE trials) which both focused exclusively on psychosocial management cost in excess of £6 million, dwarfing funding for biomedical intervention, yet both failed to show improvement on real-world outcome measures. These huge sums have taken us no nearer to finding a cure or the underlying cause.

There is a silver lining – more recently MRC funding has been targeted on more biological research, though the amounts of funding allocated are still miniscule in relation to that for other diseases

It is extraordinary to me that men and women who are trained to “First do no harm” and to “Listen to the patient for they will probably tell you the diagnosis” as well as to exclude all possible biological causes before considering psychological ones cannot but be aware of the enormous damage they are doing to a very large number – more than 200,000, patients with this condition. By recommending that too many investigations should not be conducted because they encourage illness behaviour they are risking missing vital findings of treatable conditions such as endocrine dysfunction, rarer medical conditions or

even cancers that present with chronic fatigue. How, with all the publicity, can they not be aware of the misery, neglect and, too often, abusive treatment that I can only describe as barbaric that is meted out to patients with a diagnosis of ME?

I am aware that multiple sclerosis, Parkinson's disease and diabetes were all once in the domain of the psychiatrists and that this domain is shrinking as new discoveries are made. To compensate, we have a compendium of purely subjective conditions with labels such as conversion syndrome, pervasive refusal syndrome, and neurasthenia to name but a few. There is no biological explanation for these, but they do help the uninitiated to believe that the condition is psychological.

How can we change this situation? Frantz Fanon, the French psychiatrist, philosopher and revolutionary from the middle of the last century wrote:

“Sometimes people hold a core belief that is very strong. When they are presented with evidence that works against that belief, the new evidence cannot be accepted.

It would create a feeling that is extremely uncomfortable, called cognitive dissonance.

And because it is so important to protect that core belief, they will rationalise, ignore and even deny anything that doesn't fit that core belief.”

Ladies and gentlemen, I know how very difficult it is to say “Sorry, I got it wrong”, especially when your whole career has been based on a particular belief. I have been told that, in medicine, nothing will change until the old guard moves on. The history of medicine is littered with instances of this phenomenon. It is my very sincere wish that the situation will change radically long before the changing of the guard.