

The Rt Hon Lord Bingham of Cornhill
Lord Chief Justice of England and Wales
The Royal Courts of Justice
Strand
London WC2A 2LL

24th March 2000

Dear Lord Bingham

Firstly, may I ask that you be kind enough to thank your son and daughter-in-law for allowing themselves to feature in the *Daily Mail* on 14th March --- they are very brave, and their courage and public-spiritedness will undoubtedly have done much good. I know, quite certainly, that the article has already greatly helped people in a similar situation, and it is important that people are made aware of what severe ME is really like. Most people with whom I have discussed the article have commented that despite it being said that the virus which afflicted your daughter-in-law was far more devastating than ME, what was described was ME in severe form.

Secondly, may I implore that you somehow find time to read the enclosed document *"Consideration of some issues relating to the published views of psychiatrists of the "Wessely School" in relation to their belief about the nature, cause and treatment of myalgic encephalomyelitis (ME)"*. You may be particularly interested in page 10 and in Appendix I.

Given what the Parliamentary Under-Secretary of State Lord Hunt of Kings Heath wrote to the Countess of Mar on 20th March (copy letter enclosed with Lady Mar's permission), namely *"...reviews to date have not been able to produce definitive advice as to which interventions should be recommended either to clinicians or to the NHS as a whole"*, on what legally credible grounds do these psychiatrists urge and endorse the obtaining of Court Orders to remove sick children forcibly from their parents and home for the purpose of imposing unproven psychiatric interventions?

Other than judicial review in individual cases, is there any legal approach which can be employed to stop this influential group of psychiatrists (who do not represent the view of all psychiatrists) from causing further harm to people with severe ME who are just as sick as your daughter-in-law?

Although Simon Wessely is currently claiming that there is an *ad hominem* attack upon him, it is nothing of the kind; the exposing of a genuine and significant problem with which Wessely has been personally associated for over a decade does not constitute any such personal attack, and the published evidence that such a problem exists is irrefutable.

The central issue seems to be that within the NHS there is a system which allows clinicians and researchers to impose unproven, inappropriate and potentially harmful treatment regimes on patients in an ungoverned manner, with no realistic accountability.

There is evidence that throughout the country, doctors and social workers are acting upon Wessely's advice and unproven beliefs, with incalculable harm being done to wholly innocent families as a result.

Moreover, on Wessely's advice, state benefits are withdrawn: there is a long record of the attempts made by the UK ME Association to persuade the Chief Medical Adviser to the DSS (Dr Mansel Aylward) to look at the published evidence that Wessely is wrong, but it is Wessely's input about ME / CFS which still forms the basis of the Benefits Agency Medical Services (BAMS) Guidelines for medical practitioners and adjudicating officers. Even those who, on clinical grounds, have been awarded disability allowances for life have had their benefit withdrawn because of the implementation of Wessely's personal ideology. If such

cases fight the decision and opt to appear before a Tribunal, their benefits are usually restored on obvious clinical grounds, but this represents a considerable ordeal for those who are severely sick. Some patients have even been threatened with being sectioned under the Mental Health Act unless they comply with recommended psychiatric treatment and procedures, even though their own NHS consultants have opposed such psychiatric intervention as inappropriate.

You will see from page 18 of the enclosed document that Dr Paul Cheney (referred to in the article about your daughter-in-law) says *"If you have a defect in mitochondrial function (the powerhouse of the cell) and you push the mitochondria by exercise, you kill the DNA"*. In the UK, Wessely advises Government and insurance companies that patients with ME / CFS must submit to psychotherapy which will help them abandon their "dysfunctional belief" that they are sick, and that they must exercise back to fitness; if they do not submit to such coercion, their state benefits are stopped on the grounds that they do not *want* to get better, and that by "adopting the sick role", they are enjoying "secondary gain".

A summary of cases of withdrawal of state benefit was presented to the Chief Medical Officer in person (then Sir Kenneth Calman) by the Countess of Mar, Dr EG Dowsett and Doris M.Jones MSc on 11th March 1998. Just one or two illustrations are as follows:

- (i) a female with severe ME had her benefit withdrawn but was too sick to register for employment so was ineligible for unemployment benefit; she was compelled to return home to live with her mother, a woman in her 60s who has cancer but who was forced to go out to work to support her sick daughter
- (ii) a female aged 28 (whose parents have been almost wiped out by the BSE crisis) has suffered from extremely severe ME from the age of 18 but has now suddenly had her benefits withdrawn
- (iii) a 40 year old man with three children is totally incapable of work but has now had his benefits withdrawn; his wife is suicidal.

It is the case that statistics held by the Medical Adviser to the UK ME Association show that at least one person a month commits suicide, as the pressures and battles they have to face became unbearable and in many cases they could no longer tolerate not only their acute suffering, but also the relentless harassment of Government departments with whom they were compelled to deal. Details were presented to the CMO in person on 11th March 1998.

It is the case that people with ME who have followed Wessely's regime have died as a direct consequence, but no-one will heed the evidence because it is anecdotal. One prominent Member of Parliament suffering from ME followed advice to exercise back to fitness: he collapsed and died coming out of the House of Commons gym.

There are documented accounts of people with ME having difficulties in obtaining insurance benefit for which they have contributed; there is evidence of the almost insurmountable difficulties experienced by NHS staff in obtaining early retirement on health grounds due to ME, with unfit people being forced to return to positions of great responsibility which they are simply not well enough to perform satisfactorily (including doctors, nurses, midwives, dentists, chiropractors, laboratory technicians and scientific officers).

Wessely has advised Government departments and NHS commissioning officers that no investigations should be performed on people with ME / CFS; he believes that performing investigations to look for any possible organic pathology will merely re-inforce the ME patient's maladaptive belief that they are physically sick (when he believes that they are *psychologically* ill and that they can be cured by cognitive behavioural therapy).

As a consequence of Wessely's beliefs and advice to Government bodies, there is no research, support or care available or planned for the vast majority of people with ME (see *Research Paper 98/107: Chronic Fatigue Syndrome / ME*, House of Commons Library).

That Wessely is an official government adviser on ME / CFS is not at issue, as this is confirmed in a formal letter from the DLAAB Secretariat. It is a matter of grave concern that the implementation of his unproven beliefs is not based on the freely available published scientific evidence.

In medicine, determination of the nature of the disease with which the patient presents is usually confirmed by increasingly sophisticated technical information, but this is not the case in psychiatry, where diagnosis is made by personal judgment.

Who protects sick people from someone's *erroneous* personal judgment?

Who protects sick people from a doctor's personal bias?

Who protects sick people from a doctor's ignorance and arrogance? It cannot be forgotten that diabetes, epilepsy, pernicious anaemia, gastric ulcers, Parkinson's Disease and multiple sclerosis were all classified as "psychiatric" by psychiatrists until the underlying biochemical and neurological processes were discovered, whereupon psychiatric interpretations abruptly disappeared.

Who protects sick people from medical abuse?

Are these particular psychiatrists allowed to disregard the established scientific evidence, just because it suits them not to believe it?

To whom are these psychiatrists directly accountable, or is it the case that in reality, they can do what they like? The General Medical Council is not interested; numerous attempts to bring legitimate concerns to the attention of officers of the Royal College of Psychiatrists are not even acknowledged (possibly because Wessely is a member of Council of the College) and similar representations to the Institute of Psychiatry are likewise not acknowledged (it is said by an insider that Wessely is being groomed to become Dean of the Institute).

It is on public record that the Chief Medical Officer receives a huge volume of correspondence about ME; sadly, he seems to side-step his responsibility by referring all such correspondence to the CMO's Working Group on CFS, whose Chairman (Professor Allen Hutchinson of Sheffield) has made it known that he will not hear any criticism of Wessely's work or beliefs about ME / CFS; it is also on public record that it is Wessely's own personal collection of papers which are to form the database upon which the CMO's Working Group will rely. Of concern is the fact that Hutchinson has let it be known that he has absolutely no interest in ME / CFS, and that he has no plans to be present at important forthcoming meetings of the Group, claiming that he is too busy. Certainly, he has in the past arrived late for meetings and has left early. This does not inspire confidence in his commitment to ensure that the interests of people who are severely affected by ME will be fairly represented or protected.

I am well aware that you are not permitted to offer legal advice; what I am asking for is simply information as to whom one might approach to consider this nationwide problem. For the record, people have been writing to their MP for years, with no success.

Finally, people are grateful to you for your judgment in the ME case of Page - v - Smith (12th March 1996: 3AllER 272-280, 10th July 1996); that was a very significant step in the cause of justice and medical science, and it enabled my own legal aid certificate to be re-instated in an attempt to obtain natural justice, so I am particularly grateful to you.

I look forward to hearing from you in due course.

Yours sincerely

(MW)