

THE DAILY TELEGRAPH

So don't argue with ME

Some say it's a virus, some say it's psychological. But some dare not say anything at all. DR RODNEY SILVER charts the course of a highly venomous medical campaign

MOST people suppose that the greatest threat to freedom of the press comes from the Government. The powerful generally have a vested interest in secrecy and in the suppression of information about their activities. It is true that in the past censorship was exercised principally by governments. Eternal vigilance in defence of our freedom should not blind us, however, to the existence of other less formal but more insidious threats to freedom of expression.

Sufferers from a condition now known to most doctors as Chronic Fatigue Syndrome, but to themselves as myalgic encephalomyelitis (ME), have organised themselves into an effective pressure group which has successfully restricted the open discussion of the condition in the lay press. In an age of outraged groups, their methods could easily serve as a model for others.



Picture: SIMON NORFOLK

Disorder under dispute: disagreement over the cause of ME allows sufferers to consider themselves victims of misunderstanding, prejudice and cruelty

There is no agreement over what causes ME, in which the sufferer is so weak that the slightest physical exertion is likely to render him or her exhausted for a considerable period. Some new research findings are to be announced today. Sufferers adhere, often passionately, to the theory it is the result of a viral infection. Most doctors, however, believe that it is of psychological origin.

Certainly, sufferers from ME tend to be from the higher social classes and are often conscientious people in careers which involve service to others. Perhaps their condition is the outcome of a conflict between their conscientiousness and their dissatisfaction with a life of unremitting and thankless toil. A debilitating illness of supposedly viral origin fits their bill perfectly: it enables them to retire, at least temporarily, from life, without having to admit their unhappiness.

Most doctors find this group of people intensely difficult and irritating to deal with. They often arrive in the surgery with a pile of leaflets and ask "What's your position on ME?" No one asks a doctor for his position on pneumonia or on fractures of the tibia; an *odium theologicum* is thus introduced.

For many sufferers, ME appears to be an all-consuming political cause and a way of life. It gives purpose to an existence otherwise emptied of meaning. In this respect it resembles the wilder shores of feminism, or racism awareness, more than it resembles a disease.

The extreme reluctance of ME sufferers to admit that their condition is of psychological origin dem-

onstrates that the much-vaunted acceptance by our society of psychiatric conditions is bogus. If the condition is viral in origin, it is "real" and therefore beyond an individual's control; but if on the other hand it has a psychological cause (even one amenable to physical treatment such as antidepressants), it is only an elaborate form of malingering, more a character defect than a *bona fide* illness. The sufferer should pull himself or herself together.

The disagreement over the cause of the disorder, which often leads to confrontations, allows sufferers to

Monomaniacs wish to suppress other opinions and raise the ideological temperature

consider themselves victims of misunderstanding, prejudice and cruelty: they achieve that modern state of unassailable beatitude, victimhood. This draws them together in a community of the righteous.

Whatever the truth of what causes ME (and it is important to keep a mind at least partially open, since a hitherto unsuspected virus may yet be found, and a negative in medicine is virtually impossible to prove), sufferers have managed to make their view prevail in the lay

press and television, not by force of argument but by exacting a toll on those who express contrary views. Those who have once experienced their wrath are reluctant to return to the fray. The sufferers' opinion thus goes by default.

Even the soberest of researchers, who couch their findings in dull scientific language, have found themselves subject to what can only be described as persecution. They have received unpleasant letters or been woken in the middle of the night so many times by insulting telephone calls that they have become reluctant to answer; their employers have been contacted. Many doctors to whom I have spoken, knowing the consequences, are reluctant to express their views of ME in public.

One television producer was so intimidated by the response to a programme he made about ME that he vowed never to return to the subject. He had his family to consider and was not prepared to risk their well-being over something which is, after all, only of marginal importance to most people.

Medical journalists of my acquaintance will not touch the subject because they fear the response. Since sufferers are middle class, well-connected (every judge or politician seems to have a niece with the condition), and are articulate and unafraid, it is well within their capacity to deter would-be opponents of their view. After all, sufferers care passionately about the public acceptance of ME as a viral condition; for non-sufferers, it is only one among an infinitely

large number of subjects, and not the most important.

A doctor friend who wrote in a medical journal not normally accessible to lay people received many letters, some of them wishing him dead; he was repeatedly disturbed at work by telephone calls; and complaints were made both to his employers and the Secretary of State.

When he protested to one caller about her wasting his time, she apparently replied that the harassment was only beginning and that there would soon be much more of it. His life, she said, would be made hell. The magazine in which he published his article was subjected to similar treatment, though to a lesser degree. These tactics were successful in discouraging him from returning to the subject.

An article in the *British Medical Journal* of March 19 discusses the difference between medical opinion and that which reaches the lay press; it mentions the "anger" (a laconic and understated way of putting it) which journalists who alluded to the possible psychological causation of ME has provoked from sufferers, such that two of them would never write anything again on the subject.

One must not exaggerate, of course, and there is a limit to the pressure which such a minority group can exert. Nevertheless, it is able, by exacting a personal toll on journalists, doctors and others, significantly to distort public discussion of the matter.

In this age of monomania this is alarming for those who value free-

dom of thought and expression. The numbers of people who care passionately about a single issue seems to be rising; it is tempting to speculate that such issues are a psychological substitute for religious belief, which used to give meaning to existence but is now so weakened as to be irrecoverable.

Monomaniacs wish simultaneously to suppress the others' opinions and raise the ideological temperature of the argument (how else are they to persuade themselves of its importance?). Thus they often resort to direct action, when moral terror fails: who now

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wears a fur coat in public? And on how many subjects do we find ourselves censoring not only our written word but even our thoughts?

No doubt the Government will continue to try to suppress information discreditable to itself, as governments do everywhere and always. The greatest threat to our freedom, however, comes not from that quarter but from the monomaniacs in our midst.

□ *Rodney Silver is a practising GP*