

MY RESPONSE TO MAX PEMBERTON IN DAILY TELEGRAPH 29 AUGUST 2011

<http://www.telegraph.co.uk/health/8641007/Protesters-have-got-it-all-wrong-on-ME.html>

(5th post down in 'most popular' mode)

There is so much wrong here it is difficult to know where to start, so I'm limiting my comments to a few issues. We should perhaps start though with the allegations of big bad ME patients committing "harassment, bullying and death threats". There has recently been a sustained and ongoing negative PR media campaign claiming ME/CFS sufferers and supporters are criminally harassing researchers. There are key problems with these articles/radio programmes:

1. The allegations themselves are unsafe. For example, an anonymous comment that "you will all pay" is deemed a 'death threat', when no threat is actually made, and the comment appears to denote instead a prediction of being accountable. Ironically, David Cameron used the phrase "you will pay" towards rioters recently, without it being deemed a 'death threat'.

2. There has also been a false categorisation of legitimate, non-criminal action by ME/CFS sufferers and their supporters (such as requests under FOI legislation, official complaints through various public agencies etc.) as 'malicious harassment', or 'abuse' or 'intimidation'. Legitimate actions are juxtaposed with alleged acts of criminal harassment to construct non-criminal parties as harassers.
3. These articles/programmes then go on to misrepresent any objections to psychogenic dismissal of the illnesses diagnosed as ME or CFS. Reasonable objectors have been falsely deemed 'extremist', even 'criminal', but no chance is given to such objectors to express their position. Unfortunately, the claims here about why ME patients might object to psychogenic explanations are simplistic and inaccurate.

Why DO patients object to psychogenic explanations for their illnesses? They do firstly because psychogenic explanations for somatic illnesses are often implausible, and the result of fallacious medical reasoning: a lack of bio-medical knowledge, on an individual or disciplinary level, gives rise to often increasingly absurd and confused metaphysical explanations (beliefs, lies, delusions, the awesome 'Carrie'-like kinetic power of the mind over the body to nth degrees!) by default. This leads to psychogenic dismissal of serious physical illness, so that patients' lives and health (and quality of life) are endangered. Psychogenic misdiagnoses have led to tragic, premature deaths. One example in the medical literature is a woman with Creutzfeldt-Jakob disease, who choked to death because doctors thought her illness was psychogenic: her having had difficulties with coming out as lesbian, and a difficulty in finding organic signs (eventually found, but too late for the patient) leading to this fallacious conclusion.

Accompanying psychogenic dismissal of serious illness is the use of harmful treatments, such as incremental exercise regimes for people in cardiovascular and neurological failure (if you look at the medical literature this is a phenomenon related to ME/CFS, NOT caused by 'deconditioning'), or Cognitive Behavioural Therapy that blames the patient for 'thinking' themselves ill and not being able to recover.

On top of this, patients given psychogenic diagnoses are deemed, by medics and other health workers, other state institutions such as education and social security, communities, even families, as authors of their own misfortune, as moral deviants. This leads to contempt for patients from all directions and serious mistreatment, including, for example, but in no way limited to, the withholding of benefits for people in serious need.

So, a patient facing a psychogenic explanation, whether in a media campaign like in recent weeks, in an opinion piece from a young doctor, in a clinic, is facing a HIGH potential of misdiagnosis, with a HIGH potential for serious adverse effects of this. Rationality and self-preservation will inevitably lead to protestation from patients, though they may still find themselves, at least initially, reeling from such a whirlwind of absurdity from professionals they are exhorted to trust and defer

to, and usually do.

Lastly, Max's conflation of 'mind' and 'brain' is mistaken. One is an abstract concept denoting the act of thinking. The latter is a part of the body. While the brain may enable the act of thinking, it is not the same thing as a 'mind'. Psychogenic explanations are highly problematic, and the assertion that "As a model for understanding a condition, it's as valid as any other" is sadly a declaration of uncritical faith, not of rational, scientific analysis.