

Response to Damian Thompson's article on ME

29th September 2012

On Saturday 29th September the Daily Telegraph published a blog entitled '*It's safer to insult the Prophet Mohammed than to contradict the armed wing of the ME brigade*', written by Damian Thompson.

The following letter was sent to the Telegraph letters editor in response to this blog, which can be read below.

The Letters Editor

The Daily Telegraph

29th September 2012

Sir

Is it no longer a responsible journalist's job to report facts and events accurately? Seemingly not, at least as far as the neuro-immune disease ME is concerned.

Today, Damian Thompson continues the denigration of those with ME, asserting an overlap which does not exist between "ME and eating disorders" and describing as "brave and brilliant" the bizarre speculations of an American Associate Professor of English, Elaine Showalter who, with no medical training, likened ME sufferers to those believing in "alien abduction".

A journalist concerned with accuracy would surely have taken the trouble to check and report the facts and would know that although the recent Lipkin study found no association between ME and the retroviruses XMRV or pMLV (referred to by Dr Max Pemberton in the Daily Telegraph on 24th September: "Why few dare tackle the psychology of ME – The findings of a study into the role of viruses in ME will not be acceptable to some"), the association of other viruses, in particular, enteroviruses such as Coxsackie B, is

well established.

Lipkin himself stated that patients have a particular pattern of immunoreactivity, indicating a persistent disease process, but this important finding has been ignored by those determined to dismiss ME as psychogenic.

The US Food and Drug Administration (FDA) has recently re-categorised ME under "Immune Diseases", describing it as a "serious or life threatening illness" on a par with cancer and heart failure, and the Primer for Clinical Practitioners published this month by the International Association for CFS/ME sets out evidence of multi-system disruption consistent with an autoimmune inflammatory disease.

Factual reporting would avoid the repetition of sensational claims that seem designed to provoke the very response which Thompson rightly condemns and which further fuels such discord.

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<http://blogs.telegraph.co.uk/news/damianthompson/100183212/its-safer-to-insult-the-prophet-mohammed-than-to-contradict-the-armed-wing-of-the-me-brigade/>

'It's safer to insult the Prophet Mohammed than to contradict the armed wing of the ME brigade'

September 29th, 2012 21:11

By Damian Thompson

The article you're about to read will almost certainly be referred to the Press Complaints Commission. I'll explain why later. Anyway, here goes.

This week I noticed that the Telegraph's medical columnist, Dr Max Pemberton, was being horribly slagged off on Twitter. His crime? He'd commented on the fact that scientists at Columbia University had found no evidence that two specific viruses were linked to ME, which Max described (choosing his words carefully)

as “the condition characterised by extreme fatigue and muscle pain”.

The Columbia finding was a terrible blow to many ME sufferers, who hoped that these viruses were the Holy Grail of a biological cause for their illness. But, as Max explained, it wasn't widely reported because medical journalists are frightened of the militant wing of the ME lobby.

The previous time Max wrote about ME, presenting the majority view of scientists who think the condition has a psychological component, he was targeted by people displaying what he calls “an astounding degree of paranoia and obsession”. Every article about ME provokes complaints to the PCC, but in his case those were just the start. Sinister threats and photos of Max's home were posted online.

This is a tricky subject for me, because a colleague has been diagnosed with ME. He's seriously ill: the breakdown of one part of his body after another cannot be explained by psychosomatic fatigue. On the other hand, I suspect that his condition has only been described as ME because doctors haven't pinned down what's going on.

In contrast, medical science has no great difficulty explaining what's wrong with most people diagnosed, or self-diagnosed, with ME. Their brains create a debilitating fatigue and pain that often correlates with certain personality traits. For example, there's an overlap between ME and eating disorders.

Once you start talking about overlaps you're in dangerous territory. In 1997, the feminist historian Elaine Showalter wrote a brave and brilliant book called *Hystories: Hysterical Epidemics and Modern Culture*. She suggested that “psychogenic diseases” such as ME and Gulf War Syndrome had something in common with the confabulated memories of “Ritual Satanic Abuse” and alien abduction.

Showalter was vilified for joining the dots between mysterious spasms of anxiety – but imagine the vicious treatment she'd receive if she'd written *Hystories* in the age of Twitter. As the internet sceptic Evgeny Morozov argues, social media have “overmobilised” lobby groups, whether they're Russian neofascists, climate change activists or medical conspiracy theorists.

You might say that the internet is simply enabling the free association of like-minded people. But ask yourself what like-minded people do when they connect online. They gang up on “the enemy”, whether it be a scientist exploding the myths of homeopathy or supporters of a rival football team.

In other words, much of the Twitter “conversation” is more concerned with shouting people down than opening up debate. Also, a lot of that shouting-down is organised and coordinated with an eye to twisting politicians' arms and feeding narratives to right-on media.

We'll see how this plays out. But overmobilising is already damaging the very people it's meant to help. Doctors used to regard chronic fatigue as an exciting field of research. No longer. Why? Because, to quote one of them, “it's safer to insult the Prophet Mohammed than to contradict the armed wing of the ME brigade”.