

The Media and ME

Margaret Williams 16th April 2011

Ever since the foundation of the UK Science Media Centre in 1999 – whose purpose is to ensure that the media deliver only headline science stories that accord with Government policies – the reporting of the biomedical science surrounding ME/CFS has been noticeable by its absence. Instead, there has been a wealth of spin promoting the benefits and success of CBT and GET for every disorder imaginable, including ME/CFS.

In plain terms, the Science Media Centre presents only a one-sided view of the available information about ME/CFS, and direct contact with editors and health editors of broadsheet newspapers has revealed their policy of limiting their reporting of ME/CFS to what they receive from the Science Media Centre.

The fanfare of unlimited praise for the PACE Trial results at the press conference held at the Science Media Centre on 17th February 2011 is a case in point, with the media failing to use its critical faculties and regurgitating only what it had been spoon-fed.

There are a staggering number of flaws in the PACE Trial article published in The Lancet (Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. Peter D White et al. The Lancet, 18 February 2011 doi:10.1016/S0140-6736(11)60096-2), not one of which was mentioned in the press conference.

These flaws and errors have been identified in a detailed complaint/statistical analysis sent by Professor Malcolm Hooper to The Lancet on 28th March 2011, upon which The Lancet has asked Professor Peter White to comment (a response with which Professor White has apparently not complied within the time allotted for its receipt by The Lancet).

It is understood that under the Elsevier complaints policy, Professor Hooper will be asked to respond to Professor White's reply when it is received by The Lancet; it is also understood that the PACE Trial article was to be sent for re-review by different reviewers and statisticians whilst The Lancet was awaiting Professor White's comments on Professor Hooper's complaint.

Professor Hooper's analysis will shortly be placed in the public domain; he had agreed with The Lancet to withhold his complaint from publication during the time allotted by The Lancet to Professor White to respond to it, but this agreed time limit has now expired.

There is one crucial point that should not be overlooked amidst the multitude of comments, spin, disquiet and anger surrounding the clearly contrived and exaggerated results of the PACE Trial, which is that if the PACE Trial Investigators had claimed to be studying the effect of CBT/GET on people with medically unexplained or idiosyncratic "fatigue", few people would have objected.

What is fuelling the opprobrium is the fact that the PACE Trial Investigators insist that they have been studying those with "CFS/ME", which is how they refer to the neuroimmune disorder ME/CFS.

The pressing question has to be how the Wessely School can be permitted to disregard the ever-increasing biomedical evidence-base on ME/CFS and to refuse – on no evidence whatever -- to accept the WHO classification of ME/CFS as a neurological disorder.

What can be done to halt the Wessely School's anti-science activities and misinformation about ME/CFS which they propagate and disseminate with consummate skill? Since they will not budge from their beliefs, could they be right and the biomedical scientists be wrong? Not at all: the Wessely School is gravely mistaken about the nature of ME/CFS and about their ascription of its symptomatology to a somatoform disorder.

In 1978 (33 years ago), the BMJ published a summary of the symposium on ME held that year at The Royal Society of Medicine:

" there was clear agreement that myalgic encephalomyelitis is a distinct nosological entity. Other terms used to describe the disease were rejected as unsatisfactory for various reasons: the cardinal, clinical features show that the disorder is an encephalomyelitis....Some authors have attempted to dismiss this disease as hysterical, but the evidence now makes such a tenet unacceptable....The organic basis is clear – from the finding that the putative agent can be transferred to monkeys, the detection of an increased urinary output of creatine, the persistent findings of abnormal lymphocytes in the peripheral blood of some patients, the presence of lymphocytes and

increased protein concentration in the cerebrospinal fluid of occasional patients, and the neurological findings" (BMJ 3rd June 1978).

Apart from their close involvement with the medical and permanent health insurance industry and the unpalatable fact that their professional lives may be shown to have been spent in a null field of research (ie. trying to prove that ME/CFS is an aberrant illness belief), it remains a mystery as to why, as bona fide mental health researchers, the Wessely School so persistently refuse to engage with the extensive biomedical evidence-base that exists on ME/CFS.

As Dr David Bell said in his book "Faces of CFS – Case Histories of Chronic Fatigue Syndrome" (Lyndonville, New York, 2000): *"I have no problem with not understanding the exact mechanism of the symptoms of CFS...I do have a problem with the lack of respect given patients with poorly understood neurological disease"*. Bell points out that the chest pains, racing pulse, shortness of breath, flushing, trembling, twitching, difficulty maintaining balance, headache, physiological exhaustion to the point of collapse, inability to walk, and pooling of blood on standing experienced by ME/CFS patients all result, not from what Wessely School psychiatrists deem to be deconditioning or *"hypervigilance to normal bodily sensations"*, but from the dysautonomia that is so prevalent in ME/CFS (in an effort to supply blood to the brain, the patient's blood pressure sky-rockets almost to levels that could cause a stroke but then dives, such lability being the easily confirmed hall-mark of classic ME/CFS that was identified many years ago by Dr Melvin Ramsay).

Bell explains that these symptoms are caused by elevation of adrenaline levels that are released in an attempt to compensate for impaired blood flow to the brain due to blood volume deficits and to problems in the blood vessels themselves, which result in the well-known (post-adrenaline-surge) exhaustion: *"(The blood vessels) must be constricted so tight in the brain that little blood gets through. Perhaps it is one of the hormones that constricts blood vessels. Perhaps an infection of the blood vessels. Perhaps it is an excessive sensitivity of the blood vessels to adrenaline....CFS is a devastating physiologic process that undermines the body's energy and the brain's cognitive ability....CFS is not...an illness behaviour for lazy people. The consequences of this illness weigh heavily not only on the victim, but also on family, community and society"*.

ME/CFS is an inflammatory disease (Pasi A et al. Mol Med Report 2011:4(3):535-540). Kennedy et al from the Vascular and Inflammatory Diseases Research Unit at the University of Dundee have reported a whole raft of abnormalities in adults (and subsequently in children) with ME/CFS that are consistent with vascular instability and dysautonomia. These findings include an increase in apoptosis of white blood cells; raised levels of oxidative stress which can damage blood vessels and other organs; increased markers of inflammation, and abnormalities in blood vessel function (Co-Cure RES, MED: 17th May 2010).

Another pressing question must be why the media so frequently fail to report such serious pathology in ME/CFS patients and to rely so unquestioningly on the Science Media Centre to do their work for them. Where is their own intellectual judgment and journalistic skill?

Following the NIH State of the Knowledge Workshop in April 2011, Professor Leonard Jason from DePaul University, Chicago, took part in a televised discussion hosted by Llewellyn King transmitted on 8th April 2011 (The Voice of America, episode #3012) in which Jason said that patients with ME/CFS *"get thrown to the psychiatrists....These are patients who are victimised by an illness and then the media further victimises them, and then the medical community also does it"*. Another contributor, author Deborah Waroff from New York, made the point that *"UK patients (with ME/CFS) are probably the most unfortunate in the entire world"*.

Victimisation by the media is well illustrated in the article on the PACE Trial by Adam Morris in The Edinburgh Evening News published on 15th April 2011: *"If implemented, it means patients would be placed on recovery schemes, with thousands benefitting from a new regime of exercise and a 'positive mental attitude' "*.

This statement should be compared with the comment by Professor Paul Cheney from the US on graded exercise (made in the UK at the Invest in ME conference in May 2010, proceedings of which are available on DVD from liME): *"The whole idea that you can take a disease like this and exercise your way to health is foolishness. It is insane"*.

Media coverage of ME/CFS remains problematic; comments on the PACE Trial by Vivienne Parry written for the charity AYME (The Association of Young People with ME) published on 14th April 2011 are illustrative.

Ms Parry sits on the Council of the Medical Research Council and was awarded an OBE for services to the public understanding of science. She is on the Board of the Science Media Centre, whose Science Advisory Panel includes Professor Simon Wessely. The Science Media Centre itself states: *"The team at the SMC is advised by a*

Science Advisory Panel and a Board", which would seem to indicate a close working relationship between Ms Parry and Professor Wessely.

Ms Parry is described by AYME as a *"highly respected scientific journalist"* but her comments on the PACE Trial do not assist patients with ME/CFS because many of them are inaccurate:

- it is not known *"for sure"* that two treatments (GET and CBT) are *"safe and moderately effective"* for people with ME/CFS because it cannot be certain how many patients with ME/CFS as opposed to *"CFS/ME"* were included in the PACE Trial (*"CFS/ME"* being chronic fatigue in the absence of neurological signs)
- the PACE Trial was not *"as rigorous a study as it is possible to have"*; as a respected scientific journalist, Ms Parry will know that if a trial is not a controlled trial, it cannot be so described
- it is not quite true to say that it was carried out by *"a team of experts"*, since 22 of those carrying out one arm of the trial were trainee psychiatrists employed to work at the Kings College PACE Centre, London
- APT is not the same as pacing, and pacing was not studied in the PACE Trial
- people with ME/CFS do not have *"fatigue as their main symptom"*; they have post-exertional fatigability accompanied by malaise as their main symptom (their voluntary muscles do not work properly and are exquisitely painful after exercise)
- Ms Parry says: *"There are two problems here. One is about science. Research is about coming up with a hypothesis and then trying to knock it down"*. This is precisely why the PACE Trial cannot be considered *"scientific"*. Although the Investigators' hypothesis that *"CFS/ME"* is exactly the same as ME/CFS and that it is a behavioural disorder reversible by CBT and GET was indeed knocked down by the results, the Investigators refuse to accept that the trial failed
- Ms Parry then says: *"Long held, cherished and utterly plausible ideas are regularly demolished by evidence"*. This is true, but Ms Parry fails to understand that the results of both the FINE and PACE Trials demonstrate that the Wessely School's psychosocial model of ME/CFS is wrong and has been demolished by evidence
- seemingly with no awareness of the paradox in her comments, Ms Parry continues: *"This can be incredibly disappointing but you have to move on and ask the next question, not constantly keep asking the same one in the hope that eventually you will get a different answer"*. Refusing to relinquish long held and cherished ideas about the nature of ME/CFS is exactly what the Wessely School have done for the last 25 years, and indeed they continue to do so
- Ms Parry continues: *"Some people also said that the trial was meaningless because it excluded those with a neurological disease, therefore could not have contained anyone who had ME since this is a classified neurological disease. This is a bit silly because why would you design a trial that excluded the very patients you wanted to study?"*.

The answer, Ms Parry, is simple: the Wessely School refuse to accept that ME/CFS is a neurological disorder.

As another, more informed, commentator (JT) has remarked, Ms Parry's article *"is an embarrassment....The trial was not studying the neurological disease ME/CFS but people with chronic fatigue in the absence of neurological signs, or "CFS/ME"....If the Oxford criteria had been applied correctly there would be no people present with ME....People should now be aware that the results were not clinically significant, and there remains little evidence to support the use of CBT and GET in the management of ME/CFS"*.

Is it not important that highly respected scientific journalists get their facts right and refrain from contributing to the prevailing media bias about which Professor Jason was so outspoken?

People genuinely cannot understand how individuals who profess to be speaking up for the primacy of science can defend, let alone promote, such a transparently flawed study as the PACE Trial.

The failure of CBT/GET is written in the numbers: even the skewed data presented and published in *The Lancet* show that CBT/GET are of no clinical value in the cohort studied, and certainly do not confirm that the interventions are safe and effective enough to be generalised to everyone with ME/CFS or even *"CFS/ME"*.