

Professor Peter White says clinicians should “omit the word Pacing from our lexicon”.

The British Association for CFS/ME (BACME) Conference, March 14/15, 2012

In spite of the ongoing concerns expressed by The West Midlands ME Groups [WMMEG] Consortium and over 50 UK ME Support Groups about accountability, transparency and the inappropriateness of their training and education, this year's BACME conference was once again unashamedly psychological with little or no reference to anything remotely biomedical.

The conference was facilitated by the Association of Young People with ME (AYME), who appear to be the only ME charity left standing who unreservedly support the PACE Trial.

Dr Alastair Miller who is a Liverpool Infectious Diseases consultant and the principal medical advisor to Action for ME (AfME) - even though AfME themselves appeared to have been conspicuous by their absence this time - was time keeper and introduced the speakers.

The keynote address was given by Professor Peter White, Professor of Psychological Medicine at Barts Hospital and lead researcher of the PACE trial which he described as a 'magnificent achievement'. He said PACE was a 'BACME 6-centre trial' (possibly referring to the participating NHS clinics that remain part of BACME after the CFS/ME Clinical Research Network Collaboration's transformation into BACME)

He went on to explain the need for the trial and which diagnostic criteria were used, telling delegates that the Canadian Criteria were 'impossible to use'. The trial used the Oxford criteria which were defined as "principal or primary problem of fatigue" not chronic pain, and the London ME criteria based on Ramsay -these patients needed to have post exertional malaise to meet London criteria.

Professor White discussed the results of the trial at length in an apparent bid to justify that the moderate improvements in fatigue (Chalder scale: 28 down to 20; a drop of about 7 points or so - this was conceded to be only half way back to normal) and physical functioning (20 points increase from 38 on the SF-36 scale [norm 80-85]) for Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) showed that these treatments may be used to improve the existing clinical services for ME/CFS and are safe, if delivered as described. He declared that 'Pushing limits is better than staying within limits of this illness', no doubt referring to Pacing which is the preferred coping strategy of the majority of the patients and ME/CFS Charities. He admitted that there was a 'mixed picture or no better' for anxiety, symptom count and poor concentration using these treatments.

The figures for the employment status of PACE trial participants have yet to be published, but it appears likely that they will show little or no positive difference in employment status outcomes for participants across all four arms of the trial (Standard Medical Care (SMC); SMC+ Adaptive Pacing Therapy (APT), SMC+CBT, SMC+GET)

Professor White then discussed the effect of ME organisations on the outcomes of patients that were treated by the NHS.

He appeared to blame the charities and patient groups for influencing the NHS clinics against extensive use of CBT and GET and, therefore, preventing patients from receiving 'the most effective treatments' - according to the results of the PACE Trial.

He said he did not understand why the charities don't agree with him: 'remarkably not everybody welcomed the results of the PACE trial'. Only AYME and the Sussex and Kent ME Society (both on the executive of BACME) were notable exceptions, almost every other ME organisation was against. He gave a selection of quotes following publication of the PACE Trial results - "This is not a good day for people with ME/CFS", "We find the trial results extremely worrying" ME Association; "The results are surprising and disappointing" AfME; and, (apparently a favourite) quote: "that the trial has shown the therapies to be safe and effective... is hugely damaging" AfME. He added that the charities and patients' anger is to do with stigma and fear i.e. CBT implies ME is psychological, GET implies "laziness" and getting better means it's not real and organic - if patients get better with CBT they can't have had ME to start with.

Professor White concluded that the ME charities' negative response to the 'evidence based' treatments and the PACE trial was resulting in a nocebo affect (I shall harm).