

## Prelude to the Party?

*by Margaret Williams*

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On Monday 29<sup>th</sup> November 2010 St Bartholomew's Hospital (Barts) "Fatigue Service" will be holding a combined training day and birthday party – complete with birthday cake – to celebrate 25 years of its "service" to those suffering from chronic fatigue.

Will the "party piece" be the presentation of the PACE Trial results?

Those who have not been invited to the party may still have fun by reminding themselves of some of the celebration party games that seem to be being played.

For example, the party-goers seem to believe that they are studying people with the chronic inflammatory neuroimmune disease ME/CFS (known to the party-goers as "CFS/ME") but is this just a "make-believe" party game? In reality, according to Professor Peter White's letter of 14<sup>th</sup> July 2006 to the West Midlands MREC, the party-goers have included anyone in their PACE Trial "*whose main complaint is fatigue (or a synonym)*", thereby opening the PACE Trial to anyone who is simply tired all the time (TATT); they also included people with post-herpetic (ie. post-shingles) fatigue, people with fibromyalgia (long known to be a distinct disorder, this being recently confirmed by neurologist Professor Ben Natelson: Conf Proc IEEE Med Biol Soc 2010:1:5391-5394), and perhaps even some people with ME/CFS -- in fact, it seems that everyone was welcome.

By seeming to play hearty party games and by guessing that all these different disorders are one and the same, the party-goers seem to enjoy themselves and to believe that different disorders which require different management can all be cured by one single hit (ie. convincing sufferers that they are only sick because they think they're sick). It's only make-believe, after all.



Then there seems to be the game -- and this one seems to be a real favourite -- where patients are told that their symptoms must be ignored, and that they must not seek medical help for their symptoms no matter how serious or frightening they may be -- the CBT Therapists' Manual makes it clear that there is nothing physically wrong, so there can't be anything wrong except the patients' wrong beliefs (it seems to be OK for the party-goers themselves to have wrong beliefs, all in good fun, of course).

Next comes what seems to be the real show-stopper: the party-goers seem to be playing a magical game by convincing patients that they (the party-goers) believe that the symptoms are genuine indicators of organic pathology, when they don't believe that at all. The party-goers believe that there is no pathology to account for the patients' symptoms, yet they assure patients that their illness is "real" (which patients are encouraged to believe means "physical" as opposed to "mental"), so again, it all seems to be a splendid party game.

And it seems to be such a fun game not to measure objective levels of post-intervention improvement; why bother with actometers when the party-goers can rely on measures they created themselves and when actometry might even show a worsening of symptoms? Professor Peter White knows that the pro-inflammatory cytokine TNF $\alpha$  remains elevated three days after exercise in "CFS/ME" patients (JCFS 2004:12 (2):51-66):

**Professor Peter White**

JCFS 2004:12 (2):51-66

**"We found that exercise induced a sustained elevation in the concentration of TNF- $\alpha$  which was still present three days later, and this only occurred in the CFS patients.....Altered cytokine levels, whatever their origin, could modify muscle and or neuronal function....The pro-inflammatory cytokine TNF- $\alpha$  is known to be a cause of acute sickness behaviour, characterised by reduced activity related to 'weakness, malaise, listlessness and inability to concentrate', symptoms also notable in CFS",**

but it seems to be terrific fun to pretend that this isn't of any significance and to withhold it from patients and therapists alike (the Therapists' Manual on GET is dismissive of studies showing

immune dysfunction in ME/CFS).

It's been a grand 25 years for the party-goers, even though they may not have cured a single person with ME/CFS in that quarter of a century.

Despite this, the happy party-goers seem not to have changed their belief that they are dealing with a functional somatic syndrome, so behavioural modification strategies really ought to work (the unsuccessful FINE Trial may have been just a blip that can be rectified by further and lengthier studies using the same interventions).

The privileged party-goers do seem to enjoy playing their favourite party games, but whilst they are celebrating their wonderful achievements at the top table with a birthday cake (and training others in their successful management strategies), desperately sick patients must mount their protest in the gutter.