



M.E. Analysis – Evaluating the results of the PACE study

a project supported by Phoenix Rising

1. Future studies should not use the Oxford Criteria (more)

Although she had spent her life in banking, Nora Sark had always wanted to run a zoo of her own. One day, an unexpected windfall came her way and enabled her to buy a large island. At once she set about designing and constructing numerous enclosures and, consulting her copy of "Running Zoos for Dummies", she started to build up her stock by buying breeding pairs of various species.

She was fine most of the time, and could afford to pander to their particular needs, bear the costs, and consult specialists where necessary. But some of the animals were not in her Dummies Guide, and she didn't recognise them at all.

One group bothered her in particular. These were clearly birds, but they did not seem to want to fly. She tried shooing them up ramps (Gradient Enabling Therapy), putting them in trees (Clasping Branch Therapy), or even throwing them up in the air (Airborne Projectile Therapy), but all to no avail - despite having wings, they did not fly. So she put them all together in an area she called the Completely Flightless Species, and fed them donuts. Although all of her other animals thrived, these did not.



She tried all sorts of different donuts, but nothing seemed to be successful. It was so frustrating: she couldn't work out what was going wrong.

Yes, it is a silly story, but that is how the Oxford Criteria seems to work. If patients have profound fatigue for more than 6 months, and all the standard tests come back negative, under this set of criteria they would all be diagnosed as having Chronic Fatigue Syndrome.

It is a diagnosis by default. Effectively it includes any illness of unknown cause that has profound fatigue as a persistent symptom. A diagnosed illness such as chronic heart disease, for which fatigue is a major problem, is excluded.

Approximately 40% of patients classified as having ME/CFS according to these criteria would not be recognised as having ME/CFS elsewhere in the world, where additional symptoms are required.

Yet in the UK we continue to fund research using this set of criteria.

Underpinning the philosophy of the Oxford Criteria is a profile that paints the fatigue as being principally psychological in nature (due to the absence of any clear-cut medical diagnosis). Essentially this is a diagnosis of desperation. The diagnosis does not come from observation or analysis of a patient's behaviour, but simply from a failure to find evidence suggesting an alternative diagnosis (and of course a failure to find evidence is not the same as there being no such evidence).

Increasingly there is evidence of reliable biological markers for ME, and once these are accepted, a diagnosis of ME will exclude a patient from this classification, just as it would with a diagnosis of heart disease.

Logically the current position makes no sense. A person's fatigue does not suddenly change in nature because of a diagnosis, or because a diagnosis is now possible that was not possible before. In effect a patient is judged as having a primarily psychological condition if doctors do not have the tools to diagnose an illness. The diagnosis is made from having no diagnosis, and so also includes patients for whom a full range of tests have not been carried out, those whose illness is yet to have a validated test, and those whose correct diagnosis has simply been missed.

This is risky. Recently a friend, who had apparently had ME/CFS for many years, was diagnosed as having EDS/POTS (Ehlers-Danlos Syndrome, Postural Orthostatic Tachycardia Syndrome). For him the prescribed CBT and GET had caused harm.

If it were the case that the Oxford criteria were used to define patients for whom long-term fatigue was a major factor, without any hidden assumption of a psychological profile, then there would be no logical reason for excluding other patients with such fatigue but with a specific diagnosis.

It is perfectly worthwhile to study ways of relieving fatigue in a full range of illnesses. It is perfectly worthwhile to study fatigue that is specific to one particular well-defined illness. But to separate out those illnesses for which we do not have clinical tests and knowingly lump them together makes no scientific sense.

The recently published report, the International Consensus Criteria, develops this theme much more fully for patients who have what we would call "classic ME".