

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

a project supported by Phoenix Rising

4. All patients with ME/CFS should have better access to a specialist (more)

One set of results in the PACE trial that has had less attention drawn to it is the improvement in patients' health in the group that received only Specialist Medical Care. All measures showed a small improvement for this group. In fact the average improvement with SMC alone was generally greater than the extra added on by including GET or CBT (see the table below - figures based on Table 3 of the PACE report).

With fatigue being a major consequence of ME/CFS, the initial sessions of the trial would be particularly demanding: finding one's way there, meeting and remembering new people, becoming acquainted with the procedures, and even the anticipation of taking part would all use energy. These would have a wearying effect upon anybody, whether or not they had ME/CFS, but for these patients these demands would reduce their functioning at the start of the trial. With familiarity these demands would lessen, and this would lead to an improvement in any group's scores over time, regardless of treatment.

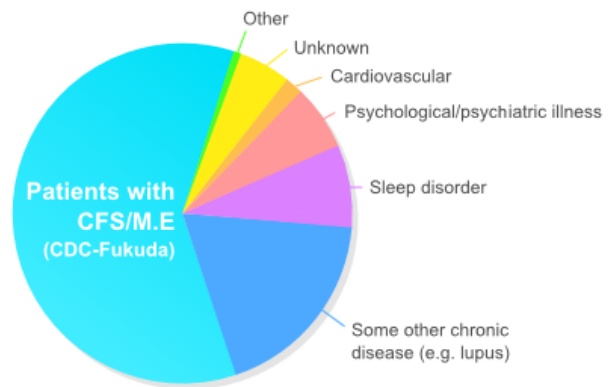
Another factor to consider is concern, prior to a firm diagnosis, about the true nature of their illness. Often the confirmation of the diagnosis of ME/CFS comes as a relief: I have met many people who were worried that they had a rapidly degenerative illness, such as Multiple Sclerosis, Early Onset Dementia, Brain Cancer or Motor Neurone Disease. For them the diagnosis of ME/CFS, understandably, came as a relief. Only much later did they realise the true implications of this diagnosis and did they have to adjust to its profound consequences.

It is not possible to assess how great these effects were, as the authors of the trial chose not to have a control group, but it would be foolish to dismiss the potential improvement that specialist care itself could have, especially with problems concerning sleep and pain. The authors of the trial pointed out that Specialist Medical Care (which all patients received) included symptomatic pharmacotherapy (especially for insomnia, pain and mood) - Panel 1 of the report; and on page 12 of the report: SMC is not the same as usual medical care that might be provided by a family doctor. In the trial, most of the patients had 3 or 4 sessions of specialist medical care, which is more than most people with ME/CFS would experience: they would usually only see a specialist for confirmation of the diagnosis (or not - see below), then be passed on to the CBT/GET team.

In 2005 I fell ill with PMR (Polymyalgic Rheumatica), for which I was prescribed steroids. My sister, living in Canada, wanted to know what my ME specialist had to say about it. I laughed. Like almost all people with ME, I only saw a specialist to get a diagnosis. There is no ongoing support or monitoring, let alone prescribing and testing out options to ease symptoms. That is why there is such a large online community trying to find remedies that ease symptoms, such as headaches, muscle pain, digestive troubles, sleep problems, etc.

	average improvement in	
	Fatigue	Physical Function
Specialist Medical Care	4.5	11.6
SMC with Graded Exercise Therapy	7.6 (3.1 added on)	21 (9.4 added on)
SMC with Cognitive Behaviour Therapy	7.4 (2.9 added on)	19.2 (7.6 added on)

In itself this small average improvement due to SMC alone would not be enough to warrant universal access to a specialist (although there is really no reason why a GP or internist shouldn't be routinely providing this level of care), but recently a report was published by the Newcastle NHS CFS Service which indicated that 40% of the patients sent to them did not actually have ME/CFS, and that was a marked improvement over previous years.



This is of great concern for two main reasons. Some patients with ME/CFS never get to see a specialist (particularly those who are more severely affected and find travelling difficult) or they experience very long waiting times – remember that often 6 months or more passes before a provisional diagnosis is made, and after that there may be a wait of a year or so. This suggests that many may live with a false diagnosis of ME/CFS. This can cause them unnecessary suffering (as many of the alternative diagnoses described in this study were more treatable).

Action for M.E. investigated the services provided in the UK under the NHS through the Primary Care Trusts in England and Wales, and published the results in their Spring 2012 magazine (issue 79). They found that only 54% of those trusts were able to state that they actually commission specialist M.E. services, and just 20% stated that they provided some form of home visit for those too ill to travel. I saw my specialist in 2001, and that was outside the NHS.

Even those patients lucky enough to live in an area that offers support services and well enough to attend, still face the lottery of how thoroughly the further diagnosis is carried out. Unlike the comprehensive testing carried out by Newcastle, many (most?) patients have perhaps a twenty-minute interview with a specialist, and are then passed on to a team trained to deliver CBT/GET.

Both of the main ME support organizations in the UK (MEA, AfME) use the estimate that there are 250,000 people with the diagnosis of ME/CFS in the UK. If we use the figure provided by Newcastle that 40% of those given that provisional diagnosis of ME/CFS turn out not to have ME/CFS, but something else, this gives us an estimate of 150,000 people who actually have ME in the UK, while 100,000 have an incorrect diagnosis. Allowing for poorer diagnosis in the past, it is likely that this is more likely to balance out at around 125,000 each. This would be similar to the estimate given by Nacul et al. of there being about 0.19%, or 118,000 actually having ME/CFS according to CDC 1994 criteria.

125,000 is a worryingly large number of people carrying a diagnosis of ME/CFS, who potentially have another, often more treatable illness.

Research from Newcastle by Hoad et al. suggests that a significant proportion of people with a preliminary diagnosis of ME/CFS suffer from Postural Orthostatic Tachycardia Syndrome. For some this may be their main problem: for others it may be just one factor in their illness. We need more evidence to determine how widespread this is, and this needs to be a part of the diagnostic process. This syndrome is explored more fully by Spence and Stewart, or there is a more everyday description from the Telegraph.

The public perception of ME/CFS can be confused by including people who have been diagnosed wrongly as having ME/CFS and who find a cure appropriate to their own different illness. Patients deserve faster and more accurate diagnosis.

A major concern as far as policy decisions are concerned is that many of the studies which inform current policy decisions were carried out when there were far fewer specialists. According to the earlier Newcastle CFS Service report mentioned above, only 36% of patients referred to them in 2007 actually had ME/CFS. If that level of error is even slightly indicative of the unreliability of provisional diagnosis of ME/CFS in earlier years, it casts grave doubt on many of the earlier studies that form the basis of our current policies.

As an example, consider how a study by Harvey et al. in 2007 which reinforced the interpretation of ME/CFS as having strong psychological underpinnings, considered the possible relationship between prior psychiatric disorder and chronic fatigue. This paper actually used self-reported ME/CFS: patients were not actually assessed for having ME/CFS; they simply recorded that they either had been told that they had ME/CFS or felt that they had it. Such reports cannot continue to be authoritative.

Access to specialist care should be made a priority for all people suspected to have ME/CFS because accurate and prompt diagnosis is essential to rational compassionate care. Whether provided through the specialist or through a GP or internist, the basic services such as those provided in the PACE trial as Specialist Medical Care – pain, sleep, and depression support as indicated – should be provided to ME/CFS patients as a matter of course.