



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

a project supported by Phoenix Rising

9. There needs to be much more research and support for the seriously affected

AfME published the results of a survey into specialist NHS CFS/ME services in the UK in the Spring 2012 issue of their magazine "InterAction".

Only just over half the trusts were able to state that they actually commission specialist M.E. services, and only 20% stated that they provide domiciliary services to those too ill to travel.

What does this actually mean to patients with ME? Most patients now get a provisional diagnosis of ME/CFS from their G.P. (the doctor at the local General Practice). Normally this takes about 6 months. For the lucky half that have a specialist centre in their area, often they are then put on that list and, around a year later, are invited to attend. There they will see a specialist for perhaps ten to twenty minutes, and have the diagnosis confirmed or not. If they have ME, they will generally then be referred to a support team of therapists, who will deal with them for perhaps 5 group sessions based at the centre, or a similar number of telephone consultations. These therapists will not be qualified to prescribe pain-killers or be qualified to help with sleep disorders. Their focus is to help each patient understand their illness, and to offer a form of CBT/GET.

A very lucky minority will be sent to a centre where they undergo thorough testing and examination by a specialist. As reported before, in section 4, Newcastle NHS CFS Service is one of these, and they found that 40% of the patients referred to them actually had another, often treatable, condition.

But what about the severely affected who cannot visit such centres? Well mostly, not a lot. Around 80% of them are with NHS trusts that do not provide domiciliary services. They do not get any access to specialist treatment. And remember – it could be that 40% or more of those do not actually have ME!

How many are there in this situation? That is very difficult to say. There are no central statistics kept on this, or, to be frank, anything much to do with ME in general. All we can do is to make educated guesses.

So start with the possible population of possibly 250 thousand (AfME and MEA estimate) having an initial diagnosis of ME. Then estimate the number that are too ill to attend a local centre - from my personal experience, where the centre is 15 miles away, but not on a convenient route for public transport, that could easily be a quarter of them. This is not the same as the proportion estimated to be housebound or ever bed-bound: much more energy and a clear head is needed to travel to such a centre. We could easily be talking of 125 thousand. Home visits are only available for 20% of them. That leaves 100 thousand without any access to specialist diagnosis or advice, and remember that it could well be that 40% of them do not in fact have ME but some other, often treatable, condition.

A hundred thousand people in the UK, pretty much isolated in their home away from society, left without any specialist medical support. How can this be right?