

The Leeds ME/CFS clinic drops Immunology cover

Margaret Williams 30th April 2012

It is noted that the Leeds clinic for CFS and ME intends to make financial savings by changing what is offered at its “specialist” clinic at Seacroft Hospital, one such change being that patients with ME/CFS will no longer have direct access to an immunologist (Yorkshire Evening Post, 28th April 2012). The Leeds and Yorkshire Partnership NHS Trust reportedly stated: *“As more is now known about chronic fatigue conditions...employing an immunologist directly is no longer necessary”*.

It is relevant that the forthcoming Invest in ME conference to be held on 1st June 2012 at Birdcage Walk in London (“Building a future for research into ME – clinical and research update in myalgic encephalomyelitis”) will focus on the disrupted immunology found in ME and to this end, a 73 page document entitled “The Immunological Basis of ME/CFS: what is already known? A compilation of documented immune system abnormalities in ME/CFS from 1983 – 2011” will be published in the conference Journal on or about 1st June and will be available online at www.investinme.org.

The lead clinician in charge of the Leeds clinic is Dr David Protheroe, a liaison psychiatrist who specialises in functional disorders (“medically unexplained symptoms”); he claims that only three percent of the clinic’s 600 patients a year engage with an immunologist.

It is interesting to recall that one of the authors of a paper published in 2010 was an immunologist and that the authors found that 40% of patients referred to a medically run specialist ME/CFS clinic were found not to have ME/CFS when appropriately investigated (JL Newton, G Spickett et al; J R Coll Physicians Edinb 2010:40:304-307).

Given the extent of the documented immune abnormalities known to exist in ME/CFS, it is a regressive step for the Leeds clinic to withdraw the services of an immunologist at its “specialist” clinic. In the light of the findings of Newton et al, how can this possibly be in the best interests of patients with ME/CFS?

It is worth recalling that as early as 1992, the Medical Research Council was aware of disordered immune function in ME/CFS: in a file of documents on ME/CFS held at the National Archives at Kew, the MRC’s own summary of the CIBA Symposium held on 12-14th May 1992 reported the following:

“Lloyd (Frederick, MD) presented data showing disordered immune responses in CFS patients”.

This file (S 1528/1), previously redacted under FOI Exemption 40 (2) was stated to be closed until 2071.

The Symposium Chairman, Dr Arthur Kleinman, a prominent psychiatrist from Boston, offered a prescient summary of the future status of ME/CFS research:

“In future, there should be integration of the approach...thus eliminating the need to define CFS as either a medical or psychiatric condition....in 10 years’ time...the central issues in the CFS field would be social rather than medical or scientific, partly driven by economics and funding of the disability systems in various countries”.

It was at this CIBA Symposium that, under the section entitled “The Treatment Process”, clinicians were instructed that:

“The first duty of the doctor is to...avoid the legitimisation of symptoms and reinforcement of disability”.

Treating ME/CFS as a functional disorder and denying patients access to immunological testing that would demonstrate underlying physical disease as will now be occurring at the Leeds “specialist” clinic effectively and conveniently avoids the legitimisation of symptoms.

The changes proposed for the Leeds ME/CFS clinic can be seen as a manifestation of the ideas presented at the CIBA Symposium in 1992, leaving patients trapped by a particular kind of circular logic: denied the appropriate medical tests to show they are physically ill, their symptoms will remain forever “medically unexplained” and thus their “treatment” will fall within the purview of liaison psychiatry which, in practice, means CBT and GET.

The PACE and FINE trials demonstrated that such approaches do not work (70% of PACE participants did not fall within the Investigators’ “normal range” after therapy), and patient surveys confirm the unpopularity of treatments predicated on the psychosocial model. When offered the choice of care by a psychiatrist or care by an immunologist, how many patients would choose the former?

The answer is most probably none, and therefore it can be seen that the pathways of care to be offered by the Leeds clinic is dictated by the exigencies of the market and not the clinical needs of people with ME/CFS.