

THE NATIONAL HOSPITALS
FOR NERVOUS DISEASES

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MEDICAL REPORT

Ean Edward Proctor
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At the request of Messrs Simcocks & Co I am writing a supplementary report, following my initial report dated 10th June 1988. I have been shown a report of Dr. D. Lewis, dated 17th May 1988.

1. Clinical history. I am in general agreement with the sequence of events as outlined by Dr. Lewis in his report. However, it is not true to state that Dr. Morgan-Hughes, Dr. Brian Lask and myself have expressed "diametrically opposed views" (paragraph 5). There are no disagreements between us in matters of substance, and our opinions concerning diagnosis and treatment are both similar and unchanged.

It is also worth pointing out that I am quoted as saying (paragraph 5) that I disagreed with Dr. Lask in that I did feel the child had ME. This is untrue, and is not found in the medical notes or my report. It is however, accurate to say that I did not challenge Mr and Mrs Proctor's own diagnosis for Ean. This was partly because it was apparent that they were not open to alternative views, but, more importantly, a label does not matter so long as the correct treatment is instituted, and this did indeed occur with everyone's agreement.

2. Myalgic encephalomyelitis. It may assist the Court to point out that I am the coauthor of several scientific papers concerning the topic of myalgic encephalomyelitis ("ME"). I am currently conducting three research projects at the National Hospital for Nervous Diseases, concerning neuromuscular function, symptomatic profiles and treatment of patients with this condition. I have been invited to present these results at an International Conference on the topic of viruses and mental health organised by the W.H.O. I am therefore well aware of the literature quoted by Dr. Lewis, and indeed have contributed to it. Dr. Lewis has experience of a community outbreak of a viral infection and its sequelae. My own experience is in sporadic cases seen in major hospitals who have been seriously ill for some time. I submit that this experience is more relevant to the case of Ean.

3. Myalgic encephalomyelitis as a diagnosis for Ean Proctor. It is certainly possible that Ean has had "ME", or as it is more properly called, the post-viral fatigue syndrome, in the past. It is essentially a clinical diagnosis as no diagnostic tests exist, but the sequence of events originally described may result from this condition. However, for the reasons that are clearly laid out in my original report, this is neither the current nor major problem.

Scientific teams in this country and also in the USA and Australia are studying this illness. None of those teams would accept Ean's current condition as being due to "ME", and all would search for an alternative

explanation. Not everyone with fatigue has "ME", and other causes for fatigue exist.

4. What is wrong with Ean? The symptom that is most distressing to Ean, his parents and medical advisers is that Ean is mute. Mutism is a specific symptom with specific causes. It can be due to a central lesion, such as a stroke, but the normal brain scans exclude this. It can be due to a muscle weakness, as acute-infectious polyneuropathy, but then Ean would require artificial respiration. It is therefore impossible that Ean's mutism is due to a primary neurological illness.

Mutism can also result from a psychiatric illness, either abnormal illness behaviour or depression. Dr. Lewis states that Ean's loss of speech is due to abnormal illness behaviour. Dr. Lask feels that depression is also important, but the two views are not exclusive. I have considerable experience of both the post-viral fatigue syndrome and child and adult psychiatry, and would submit that mutism does not, and cannot occur, in a true chronic fatiguing illness, but can, and does occur, in psychological illnesses.

5. Treatment. I am in agreement with most of the points made by Dr. Lewis concerning subsequent treatment, in particular that Ean should not remain in bed and will require some form of physiotherapy. I disagree however that active rehabilitation should wait until recovery has taken place, and submit that recovery will not occur until such rehabilitation has commenced. I would again emphasise that delay may lead to further medical and psychological complications. Ultimately it does not matter what diagnosis is given to Ean, so long as help is forthcoming soon.

6. Treatment of "ME". In my original report I have not stated my views on the treatment of "ME", as I did not consider it relevant. However, it may help the Court to emphasise that there is considerable disagreement concerning the appropriate treatment for this syndrome. We now have increasing expertise in the management of individuals presenting with fatigue, either of unknown cause or ascribed to the post-viral fatigue syndrome. I would emphasise that active management, which takes both a physical and a psychological approach, is the most successful treatment available. The need to combine a physical and psychological approach is now accepted by most authorities working in this field. There is little scientific evidence that such an approach may be detrimental and considerable evidence to suggest otherwise. We are currently conducting a formal evaluation trial, and I have no reason to alter this view.

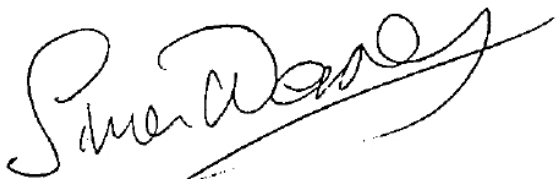
7. What has gone wrong? The diagnosis of "ME" was originally made by Ean's family. It was a reasonable view in the early stages of Ean's illness, but is no longer accurate. Parents, even well-informed, are not necessarily the best judges of diagnosis which is a medical and not a legal matter.

The problem is that wider issues have become involved. There is a real and serious danger of Ean becoming a "cause celebre" in the debate concerning "ME". I realise that Ean's parents are only motivated by a desire to help Ean, but involving this child in the debate is not in his interests. Furthermore, the longer this situation goes on for, the more "hardened" attitudes will become, and the less the possibility of a compromise occurring that will benefit Ean. It is appalling that he has become the victim of the debate into the existence of "ME". I do not doubt

the reality of a chronic fatigue syndrome, but I do not think that is the main problem with Ean.

I am very alarmed by what I have read in the popular press concerning this case. It is thus regrettably necessary to point out that I investigate, diagnose and treat cases of post-viral fatigue. I would not be wasting my energies and career on a condition if I did not think that it had scientific validity.

8. Conclusions. This is a tragic case. I totally agree with Dr. Lewis' view that everyone involved in Ean's care, including Mr. and Mrs. Proctor, are only motivated out of the best interests. For this reason, a Court of Law should not be the place where essentially medical matters are settled. I hope therefore that agreement can be reached between Mr. and Mrs. Proctor, and the doctors who are trying to care for Ean. I also hope that Mr. and Mrs. Proctor will feel able to accept that Ean has probably had the post-viral fatigue syndrome as described, but has now developed a serious secondary psychological complication. I hope they will accept that this is a common and recognised sequence of events and implies no criticism of either themselves or Ean. It is now in everyone's interests that rehabilitation proceeds as quickly as possible to enable Ean to return to full health. I am sure that everyone, including Ean, is now anxious for a way out of this dilemma with dignity, and I believe that views expressed in this report represent the safest and speediest way that this may be brought about.



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