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23 August 2009



Ciaran Farrell – Coherent Overview NICE CFS/ME Guidelines Judicial Review

By Jane Colley, Parent

I believe that in his recent document [“Ciaran Farrell On Malcolm Hooper, 'Margaret Williams' And The NICE CFS/ME Guidelines Judicial Review”](#) Mr Farrell has provided us with a coherent overview of how the Judicial Review of the NICE Guidelines on CFS/ME was lost.

Failure to observe the protocols and procedures required when going to law is unforgivable. This judicial review was far too important to all those who are ill with ME/CFS for such fundamental errors of judgement to have been made.



Professor Malcolm Hooper – Tarnished Reputation

Prof Hooper in his statement of 19 August listed the ME Charities which supported the case put forward by the law firm of Leigh Day. The granting of the [Wasted Costs Order](#) will undoubtedly have tarnished the reputation of each and every one associated with this sorry affair.

I should like to thank One Click for the initiative they took which ensured that a Judicial Review of the NICE guidelines took place. As one of the pledgers, I shall always be grateful for the commitment they showed to us and for the fact that as the Interested Party they and their lawyers respected the law and behaved with integrity. [See [How The Judicial Review Of The CFS/ME NICE Guidelines Was Lost](#)].

Tragically, it is the ME patients who will be the ones most damaged by all of this as the genie is about to be well and truly let out of the bottle.

The M.E. Charities And The Clinics

The ME/CFS clinics are pretty much in place, and the ME charities have played their part in their establishment. A few years ago the members of the children's charity we belonged to were encouraged to have their say. My daughter appears on the front cover of one such document. See Tymes Trust, on the ME Clinics [here](#).

Little did we know then that the real purpose of such clinics would be to dole out CBT and GET prescribed under the NICE guidelines, Had we been aware that somehow we were giving our tacit approval to any of this, I am certain most of us would have been horrified.

Very shortly doctors will be required to use the NICE guidelines when treating their ME/CFS patients. All the ME charities state that CBT and GET are unsuitable for many of their members. Perhaps, even at this eleventh hour, these charities could do something constructive to help their members before they are forced to undertake treatment which could potentially make them much more ill.

I believe they could do something to redeem themselves by widely publicising a test which is already available. In her excellent paper of 2009, Dr Myhill explains how this test works. The results can be used to demonstrate whether a patient with an ME diagnosis is physically ill. The science used in this test comes straight out of the top drawer as the scientists behind the chemistry were awarded the [1997 Nobel Prize for Chemistry](#). [See '[Chronic fatigue syndrome and mitochondrial dysfunction](#)', Sarah Myhill¹, Norman E. Booth², John McLaren-Howard³, Int J Clin Exp Med (2009) 2, 1-16].



Dr Sarah Myhill, MB BS

My daughter had this test carried out on her nine years after she became ill. It demonstrated that her cells were blocked and her ATP/ADP conversion was very poor. (Interestingly, when she was 14 and was learning about aerobic and anaerobic respiration at home with a text book, she had told me that she knew that her body often switched over to anaerobic respiration). At around the same time as she had

the test done we discovered that the underlying cause of all her ME symptoms was an untreated bacterial infection.

Thirty months after completing extensive treatment, she is absolutely fit and happy, working full time whilst studying with the OU.

CBT/GET must be kept for those with a psychological illness as those who are physically ill need the underlying causes of their illness to be addressed before they can become more well. At least if a patient has had this test done they have something which proves that their illness is not all in their head.

Jane Colley
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Related Links:

- * ['Chronic fatigue syndrome and mitochondrial dysfunction'](#),
Sarah Myhill¹, Norman E. Booth², John McLaren-Howard³, Int J Clin Exp Med (2009) 2, 1-16.
- * [Ciaran Farrell On Malcolm Hooper, 'Margaret Williams' And The NICE CFS/ME Guidelines Judicial Review](#)
Ciaran Farrell, Health Advocate
- * [Professor Malcolm Hooper - Intolerable ME/CFS Hypocrisy](#)
Lara, Health Advocate
- * [How The Judicial Review Of The CFS/ME NICE Guidelines Was Lost](#)
Jane Bryant, The One Click Group
