

COMMENTS ON RECENT OUTPUT BY ONECLICK

DM Jones MSc

23rd January 2005

Various contacts have kindly forwarded to me a considerable number of documents and comments in relation to recent output by ONECLICK in response to Margaret Williams' statement on their ill-founded and unjustified criticisms of the charity MERGE following the release of the RCPCH Guidelines on management of children with ME/CFS. Those documents included a response from Stephen Ralph to further undeniably vitriolic reactions from ONECLICK.

I have been greatly saddened to see much time and effort spent on disputes which should never have arisen. I have thought long and hard whether to make any comments on these exchanges, but having fallen out of favour with ONECLICK after a short but very hectic association, I have decided to make a few comments.

After ONECLICK came into being, I along with others was persuaded to cooperate with those who run this advocacy group, in the hope that their efforts might make a necessary and useful contribution in exposing much that has gone wrong in the treatment and care of adults and children with ME/CFS. Being a carer of a child who developed ME in 1980 (now thankfully recovered to a significant degree), having studied the subject at postgraduate level and since, having been a Reference Group member of the CMO's Working Group on CFS/ME, who submitted numerous documents to this group, and someone who has shown results of independently conducted studies and surveys at six international conferences and had many articles on this and related subjects published, I believe that I am regarded by some as one of the 'veterans' in this field.

In that capacity and hopefully in the best interest of many sufferers, I provided whatever information I could to ONECLICK during my short association with them last year, often at considerable inconvenience and working late into the night. I have worked on a similar basis with other contacts and in many cases this collaboration has resulted in a mutually beneficial and indeed positive and productive documentation of many facts and data, which I don't doubt the history of the ME/CFS saga will eventually reveal. Such exchanges, however, invariably and of necessity include at times critical appraisal of factual accuracy and indeed differing viewpoints. When these are given in good faith and taken in the spirit in which they were made, the outcome is inevitably positive. However, this generally accepted practice badly backfires if one of the parties involved consistently misinterprets comments and considers genuine and well-meant advice as personal insults, as regrettably invariably is the case with ONECLICK.

Margaret Williams in her recent critique has cited numerous incidents when Jane Bryant, one of ONECLICK's directors, felt obliged to engage in personal insults and accusations over some event or occurrence which met with her disapproval, including some comments made in respect of the incident which led to my own dissociation with ONECLICK. Whilst these quotes do not give the full 'saga', they were nevertheless made and are correctly cited. I cannot vouch for the correctness of other citations, but have no doubt that they, too, were correctly quoted.

ONECLICK have repeatedly stated they would rebut many false accusations levied against them by releasing countless e-mails and other documents. Were they to do so, I greatly doubt that many people would be either interested or take the time and trouble to read them. All that sick people want is some help and advice on how to get better and where to get good advice on more appropriate treatment than is currently available to them on the NHS.

In summary, I would like to make the following points, in the hope that ONECLICK will take time to reflect seriously on their own position and consider the fuller picture in relation to the deplorable situation in which so many severely ill ME/CFS patients now find themselves:

1. There are many individuals and some organisations who, prior to the existence of ONECLICK, have done much work to advance the understanding of ME/CFS and related disorders (such as MCS/FMS/GWS etc), as well as expose the inexcusable misrepresentation of these problems by certain UK psychiatrists. Without their freely-given help and support, ONECLICK would have found it much more difficult to get established and this should not be forgotten.
2. Whilst the two major UK ME/CFS Charities must undoubtedly shoulder much blame and responsibility for not adequately and appropriately representing the best interests of their members – mostly sick patients or their carers, the situation for smaller organisations, like The 25% ME Group, The Meach Trust, MERGE, BRAME, RiME and others, is of necessity quite different, not to mention the roles played by individuals like Margaret Williams, Stephen Ralph or even myself, and not forgetting people like Dr Betty Dowsett, Professor Malcolm Hooper, Dr Vance Spence and others. Each of the above mentioned performs a certain function and their individual influence on government policy is of necessity marginal. If all these smaller groups and individuals either work together, or at least support each other as much as possible – always bearing in mind that many are very sick people – their combined efforts may and hopefully will eventually bring some results. However, if one of the self-styled campaigning organisations decides to ‘throw the spanners in the wheels’ in a glare of unproductive publicity the moment something does not go the way they demand, then the overall impact will undoubtedly be greatly diminished if not wiped out entirely (‘United we stand, divided we fall’ – the Trade Union principle).
3. ME/CFS and other so-called ‘modern diseases’ mentioned above, are highly complex medical phenomena. The number of GPs and other health care professionals who have any idea of how to treat such patients is pitifully small. Even a most sympathetic GP at the present time is unlikely to be able to prescribe drug(s) or recommend a remedy which will bring about a rapid and lasting improvement in the condition of such patients. This is a simple statement of fact. Clearly a huge amount of work needs to be done in this field. I therefore think it is irresponsible and counter-productive to jeopardize the small chances of any advancement in the biomedical field, such as those which the charity MERGE is working on, by such public and destructive attacks as those recently released by ONECLICK.

23.1.2005.