

Some Documents of Relevance to the ME/CFS Community

ENGAGING WITH MYALGIC ENCEPHALOMYELITIS: Towards Understanding, Diagnosis and Treatment Malcolm Hooper February 2003

Obtainable from M Hooper, Emeritus Professor of Medicinal Chemistry, School of Sciences, Fleming Building, Wharncliffe Street, University of Sunderland, SR2 3SD at a cost of £4.50 including postage.

This 85 page publication deals in depth with the disordered biochemistry found in ME/CFS; with the gut-brain axis; with immune system dysfunction seen in ME/CFS; with dysfunctional metabolism and oxidative stress seen in ME/CFS and with impaired membranes in ME/CFS and offers sound practical advice about restoration of these dysfunctional systems. Fully referenced with colour plates.

A MILLION STORIES UNTOLD Jodi Bassett February 2004 (posted on Co-Cure EDU 2nd April 2004 / <http://tertius.net.au/foohold/untold.html>).

This compelling 14 page document is a moving and factual account of the effect of ME/CFS. It conveys the brutal reality and the tragedy of living with a serious physical disorder with, at best, little medical or social support and at worst, denial of its existence. It quotes several internationally renowned ME/CFS experts including Professor Leonard Jason (“this disease, this syndrome, is actually more debilitating than just about any other medical problem in the world”); Dr Dan Peterson (“When asked on CNN how many of his (ME/CFS) patients had fully recovered in fifteen years, Dr Peterson chillingly stated ‘None’ ”) and Dr Mark Loveless, Head of the AIDS and CFS Clinic at Oregon Health Sciences University, who in 1995 testified at a congressional briefing that an ME/CFS patient “feels effectively the same every day as an AIDS patient feels two months before death”). It lists the evidence of physical abnormalities seen in ME/CFS (for example, Dr Paul Cheney found that in dual chromatography analyses, many ME/CFS patients had more biochemical derangement of the brain than patients with Parkinson’s or Alzheimer’s disease) and it considers the abuse experienced by ME/CFS sufferers at the hands of those professionals who find that dismissal of the disorder better serves their own purposes. Referenced.

25% ME GROUP ANALYSIS REPORT 1st March 2004

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This document analyses a questionnaire entitled “Essential Services for Severely Affected ME Sufferers”. It highlights for MPs, healthcare professionals and Social Services staff the lack of services for those with severe ME/CFS. It deals with difficulties experienced with state benefits, social services, homecare support

requirements, carers' needs, Primary Care Trusts, hospital referrals and treatments, optical and dental services and with management approaches that have been found to be unhelpful (particularly cognitive behavioural therapy and graded exercise programmes). It is clear that patients with severe ME still face considerable difficulties in gaining access to necessary basic services.

SPEECH TO SCOTTISH PARLIAMENT Jane Colby, Executive Director of The Young ME Sufferers Trust (Tymes Trust) 24th March 2004
Tymes Trust, PO Box 4347, Stock, Ingatestone, Essex, CM4 9TE
Tel/Fax : 01245 401080 <http://www.tymestrust.org>

This document blows the dust away and exposes the determined efforts that have been made by both the CMO's Working Group and the two major UK ME charities to suppress the physical reality of ME/CFS. It reveals the culture in the ME charity world of a desire "not to rock the boat" and not to tell the truth but to placate the psychiatric lobby at all costs. It documents the great concern by patients that the new clinics (to be funded by a Government injection of £8.5 million) are set to deliver nothing but the favoured psychiatric regimes (the published aims of which being to amend ME/CFS sufferers' "dysfunctional" and "aberrant" beliefs that they are suffering from a physical disorder). It sets out how children and young people with ME/CFS are still being forcibly removed from their parents and that such proceedings are supported by Wessely School psychiatrists (whose published views are that ME is a "myth" and that in reality, it is a non-existent disease and "CFS" is a somatoform disorder). It documents the blatant injustice against children with ME/CFS, against their parents, and even against doctors who dare to defend them. It records that such injustices are increasing. It states "We at Tymes Trust are at a loss to see what possible advantage can be gained by refusing to face the reality of the dire things that are still happening to adult patients and to children. Despite the fact that these cases appear to grow in number, the reality is denied by the very ME organisations who should be protecting the children and publicising what is going on. It is not by sweeping such things under the carpet that we shall eventually prevent them happening".

The following documents all have the same theme but document different aspects. Bound copies are available at cost price plus postage from either the Countess of Mar, House of Lords, London SW1A 0PW or from Doris M Jones MSc, 176 Perth Road, Ilford, Essex, IG2 6DZ (UK). Also available online.

DENIGRATION BY DESIGN? Vol I (1987-1996) August 1996 (pp 217)
DENIGRATION BY DESIGN? Vol II (1996-1999) December 1999 (pp 271)
A Review, with References, of the Role of Dr (now Professor) Simon Wessely in the Perception of Myalgic Encephalomyelitis Eileen Marshall, Margaret Williams

<http://www.btinternet.com/~severeme.group/contents.htm>

http://www.btinternet.com/~severeme.group/denigration_extra1.htm

Volume II contains several appendices, including:

- (i) The Views of Dr Simon Wessely on ME: Scientific Misconduct in the Selection and Presentation of Available Evidence?
- (ii) Summary of some of the findings presented at the Second World Congress of ME/CFS, Brussels, September 1999
[http://www.meactionuk.org.uk/Brussels_1999_\(separate_document\).htm](http://www.meactionuk.org.uk/Brussels_1999_(separate_document).htm)
- (iii) Recommended Reading
- (iv) Notes on Human Herpes Virus Type 6 research on ME/CFS

Both volumes contain a selection of published articles on ME/CFS (showing its organic pathoaetiology) with which Wessely et al disagree, and document the relentless onslaught on ME/CFS sufferers by Wessely et al, resulting in the now prevailing misinformation about the disorder. Both volumes fully referenced.

CONSIDERATION OF SOME ISSUES RELATING TO THE PUBLISHED VIEWS OF PSYCHIATRISTS OF THE “WESSELY SCHOOL” IN RELATION TO THEIR BELIEF ABOUT THE NATURE, CAUSE AND TREATMENT OF ME

March 2000 Margaret Williams

<http://www.meactionuk.org.uk/consideration.htm>

This 65 page document exposes and details the tactics of denial and dismissal of the international biomedical evidence of the organic basis of ME/CFS used by this group of UK psychiatrists and contains appendices by Val Broke-Smith (Special issues relating to the treatment of children and young people with ME) and Ann Crocker (Open letter to the Chief Medical Officer). Fully referenced.

CONCERNS ABOUT THE FORTHCOMING UK CHIEF MEDICAL OFFICER'S REPORT ON ME AND CFS, NOTABLY THE INTENTION TO ADVISE CLINICIANS THAT ONLY LIMITED INVESTIGATIONS ARE NECESSARY

July 2001 Sally Montague Malcolm Hooper (known as the Montague / Hooper paper).

[http://www.meactionuk.org.uk/Comments_on_advice_given_\(by_a_member_of_the_Key_Group\).htm](http://www.meactionuk.org.uk/Comments_on_advice_given_(by_a_member_of_the_Key_Group).htm)

This 22 page document was submitted to the CMO's Working Group before publication of the final report but was repeatedly ignored. It challenges the psychiatric lobby which dominated the CMO's Working Group and it questions the robust support of Dr Charles

Shepherd (a member of the CMO's Key Group, who at the time was Medical Director / Adviser to the UK ME Association) for the Wessely School psychiatrists' views that only limited investigations are appropriate and necessary for those with ME/CFS, when this advice flies in the face of the international evidence that basic screening is insufficient for such patients. It includes evidence of published international research findings on ME/CFS that those psychiatrists are intent on ignoring, including abnormalities seen in brain studies; in neurological investigations; the visual processing disabilities experienced by ME/CFS patients; the abnormal biochemistry exhibited in these patients; the genetic abnormalities demonstrated in these patients, as well as the abnormalities found in virological, microbiological and immunological studies; it sets out the urgent need for comprehensive investigations of ME/CFS patients as well as the need for sub-grouping. Fully referenced.

CONCEPTS OF ACCOUNTABILITY? August 2001
Sally Montague Malcolm Hooper.

http://www.meactionuk.org.uk/CONCEPTS_OF_ACCOUNTABILITY.htm

This 69 page document outlines some of the background that lay behind the writing of the Montague / Hooper paper and was produced because, following the release of the Montague / Hooper document, the authors and their associates were subjected to a furious and sustained attack (including threats of legal action) by Dr Charles Shepherd (then Medical Director / Adviser to the UK ME Association) and other members of HealthWatch (a campaigning organisation known for its history of zealously attacking environmental medicine as well as alternative and complementary health practitioners and which has accepted money from both the pharmaceutical and insurance industries). The document sets out the evidence that ME/CFS may be either virally or chemically induced; it sets out the evidence supporting the need for sub-groups of "CFS"; it considers the undeclared competing vested interests of the most influential members of the CMO's Working Group; it examines the psychiatric bias of the 1996 Joint Royal Colleges' Report on "CFS"; it discloses the actions of Dr Shepherd after the release of the Montague / Hooper paper; it considers HealthWatch and its published views on ME and it documents the actions of some of the medical members of HealthWatch in relation to their dismissal of environmental illness; it considers the blatant attempts to re-classify ME/CFS from neurological to psychiatric by Wessely et al and it briefly sets out support for Professor Hooper. Fully referenced.

COMPOSITE RESPONSE ON THE FINAL VERSION OF THE CMO'S REPORT OF 31ST AUGUST 2001 ON CFS/ME. September 2001. edited by Malcolm Hooper

<http://www.meactionuk.org.uk/CompositeResponse.htm>

This 39 page document analyses the final version of the Report of the CMO's "independent" Working Group on "CFS/ME" and comments on all sections of the draft report which ignore or dismiss the evidence of an organic pathoaetiology in ME/CFS; it presents illustrations of the evidence that was ignored in the compilation of the CMO's Report. Fully referenced.

WHAT IS ME? WHAT IS CFS? INFORMATION FOR CLINICIANS AND LAWYERS December 2001 EP Marshall M Williams M Hooper

http://www.meactionuk.org.uk/What_Is_ME_What_Is_CFS.htm

This 26 page publication contains sections on the history, description and symptoms of ME; evidence of abnormalities and physical signs found in ME; history of Chronic Fatigue Syndrome; how CFS displaced ME in the UK and information on the UK Chief Medical Officer's Report on "CFS/ME". It urges the need for caution by both clinicians and lawyers. Fully referenced.

RESPONSE TO THE MRC RESEARCH ADVISORY GROUP (RAG) DRAFT DOCUMENT FOR PUBLIC CONSULTATION ON CFS/ME DATED 17TH DECEMBER 2002 27th December 2002 M Hooper EP Marshall M Williams

http://www.meactionuk.org.uk/Initial_Comments.htm

This 26 page document considers and comments upon the draft document produced by the Medical Research Council RAG on the MRC's preferred (psychiatric) strategies for the management of "CFS/ME" and it provides evidence already published in international mainstream medical journals (over 60) that document organic anomalies in ME/CFS which the MRC RAG members had persistently chosen to ignore. On the basis of what they have previously published, it reveals the psychiatric bias of the carefully chosen members of the RAG. Fully referenced.

NOTES ON THE INVOLVEMENT OF WESSELY et al WITH THE INSURANCE INDUSTRY AND HOW THEY DEAL WITH ME/CFS CLAIMS

17th June 2003 M Williams

http://www.meactionuk.org.uk/Notes_on_the_Insurance_issue_in_ME.htm

This 21 page document lists the insurance companies known to be involved with ME/CFS claims and considers the known involvement of the Wessely School psychiatrists with such claims. It sets out the known concern of Members of Parliament about the difficulties experienced by those with ME/CFS when making legitimate

insurance claims. It provides illustrations of Wessely's control over the national perception of ME/CFS. It quotes from psychiatrist Michael Sharpe's contribution in UNUMProvident's "Trends in Disability 2002" which confirms that PRISMA (a commercial healthcare company of which Professor Simon Wessely is a member of the Supervisory Board) is now providing "rehabilitation regimes" (based on a more than usually intensive cognitive behavioural programme designed by Wessely et al) for the NHS for claimants with ME/CFS. It contains two Statements from ME/CFS sufferers setting out the difficulties they have encountered with their insurance claims caused by named Wessely School psychiatrists.

**THE MENTAL HEALTH MOVEMENT: PERSECUTION OF PATIENTS?
A CONSIDERATION OF THE ROLE OF PROFESSOR SIMON WESSELY AND
OTHER MEMBERS OF THE "WESSELY SCHOOL" IN THE PERCEPTION OF
MYALGIC ENCEPHALOMYELITIS (ME) IN THE UK**

December 2003 Professor M Hooper in conjunction with the UK ME/CFS community

http://www.meactionuk.org.uk/SELECT_CTTEE_FINAL_VERSION.htm

This 75 page document asks if powerful and influential psychiatrists who dominate the perception of ME/CFS in the UK are working within the Mental Health Movement which is known to be linked to the multi-national corporations that now control medical and research institutions and whose life-blood is profit, and if the determining factor governing policies on medical research and on the management of patients is increasingly determined not by medical need but by economic considerations. It looks at Wessely's involvement. It looks in detail at the tactics of denial used by psychiatrists of the Wessely School in their denial of the reality of ME/CFS as a physical disorder and at their insistence that it is a psychiatric disorder. It looks at the House of Commons Report from the Select Committee on Science and Technology that was excoriatingly critical of the MRC during the time that Wessely was a member of three MRC Boards. It looks at Wessely's influence over the national and international mis-perception of ME/CFS. It includes two appendices, one of quotations from the published works of Simon Wessely on ME/CFS and one of the published works of Michael Sharpe on ME/CFS, which speak for themselves. Fully referenced.

An illustration of the pervasive influence of Wessely School psychiatrists is to be found in an article in the Belfast Telegraph on 5th April 2004 ("ME and you")

<http://www.belfasttelegraph.co.uk/news/features/story.jsp?story=508694>

which quotes the consultant psychiatrist in charge of sessions of cognitive behaviour and exercise therapy for ME/CFS patients in Northern Ireland, Dr Noel Scott from Belfast City Hospital, as stating "These people need to have their attitudes changed".

Those who find it difficult to accept that these psychiatrists do indeed have their own agenda, and that the very people who are tasked with supporting patients with ME/CFS are actively militating against them, may be assured that the evidence exposing their duplicity is incontrovertible but is not yet in the public domain.

7th April 2004