

Magical Medicine:

How to make a disease disappear

PRESS RELEASE: MEDICAL RESEARCH COUNCIL

12th February 2010

A formal complaint has been lodged by Professor Malcolm Hooper with the Rt. Hon The Lord Drayson, Minister of State with responsibility for the Medical Research Council (Science and Innovation) about the “PACE” Clinical Trial of behavioural modification interventions for people with Myalgic Encephalomyelitis (ME) / Chronic Fatigue Syndrome (CFS).

PACE is the acronym for **P**acing, **A**ctivity, and **C**ognitive behavioural therapy, a randomised **E**valuation, interventions that, according to one of the Principal Investigators, are without theoretical foundation.

The MRC’s PACE Trial seemingly inhabits a unique and unenviable position in the history of medicine. It is believed to be the first and only clinical trial that patients and the charities that support them have tried to stop before a single patient could be recruited and is the only clinical trial that the Department for Work and Pensions (DWP) has ever funded.

Since 1993, the giant US permanent health insurance company UNUMProvident has been advising the UK DWP about the most effective ways of curtailing sickness benefit payments. The PACE Trial is run by psychiatrists of the Wessely School, most of whom work for the medical and permanent health insurance industry, including UNUMProvident. These psychiatrists insist – in defiance of both the World Health Organisation and the significant biomedical evidence about the nature of it -- that “CFS/ME” is a behavioural disorder, into which they have subsumed ME, a classified neurological disorder whose separate existence they deny. Their beliefs have been repudiated in writing by the World Health Organisation.

In 1992, the Wessely School gave directions that in cases of ME/CFS, the first duty of the doctor is to avoid legitimisation of symptoms; in 1994, ME was described by Professor Simon Wessely as merely “a belief”; in 1996 recommendations were made that no investigations should be performed to confirm the diagnosis and in 1999 patients with ME/CFS were referred to as “the undeserving sick”.

The complaint is supported by a 442 page Report which addresses areas of major concern about the PACE Trial.

These include apparent coercion and exploitation of patients, flawed methodology, apparent lack of scientific rigour, apparent failure to adhere to the Declaration of Helsinki, the unusual personal

financial interest of the Chief Investigator, the vested financial interests of the Principal Investigators and others involved with the trial and the underlying non-clinical purpose of the trial.

The psychiatrists' unproven beliefs and assumptions are presented as fact and trial therapists have been trained to provide participants with misinformation; therapists have also been trained to advise participants to ignore symptoms, a situation that may in some cases result in death.

There are some extremely disquieting issues surrounding the MRC PACE Trial and documents obtained under the Freedom of Information Act allow the full story to be told for the first time.

People with ME/CFS do not seek any special consideration; they simply wish to be treated equally to those who suffer from other classified neurological disorders. As shown in the Report that accompanies the complaint, the MRC PACE Trial clearly demonstrates that people with ME/CFS are not treated equally to those with other chronic neurological disorders.

The Report can be accessed at <http://www.meactionuk.org.uk/magical-medicine.pdf>

File Size 6Mb

Adobe Acrobat format

CONTACT: Professor Malcolm Hooper Tel. +44 191 528 5536

See alternative download sites below

See also: Letter to Sir Michael Rawlins - Chairman of NICE here

and

e-mail addresses for Magical Medicine Distribution

Letter of complaint to the Rt Hon The Lord Drayson

Ph.D.,B.Pharm.,C.Chem.,MRIC

Sunderland

SR3

Professor Malcolm Hooper

11th February 2010

The Rt Hon The Lord Drayson

Minister of State
(Science and Innovation)
1, Victoria Street
London
SW1H 0ET

Dear Minister

re: **Complaint about the Medical Research Council**

It is with deep concern that I lodge this formal complaint about the Medical Research Council with you in your capacity as Minister with responsibility for the MRC.

You will doubtless be aware of the serious problems at the MRC that were documented in the 2003 Report of the House of Commons Select Committee on Science and Technology (HC 132) in which MPs issued a damning judgment on the MRC, lambasting it for wasting funds and for introducing misguided strategies for its research. MPs found evidence of poor planning and of focusing on “politically-driven” projects that have diverted money away from top-quality proposals. The unprecedented attack was the result of a detailed probe into the workings of the MRC. Sadly, very serious problems continue to exist at the MRC, with disastrous results for patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome.

The attached 442 page Report addresses the background to the MRC “PACE” Trial on “CFS/ME”, the biomedical evidence that disproves the assumptions of the MRC trial Principal Investigators, the many extremely disturbing issues surrounding the PACE Trial, and illustrations from the Manuals used in the trial.

The unproven beliefs and assumptions of the MRC Investigators are presented as fact; trial therapists have been trained to provide participants with misinformation, and therapists have also been trained to advise participants to ignore symptoms arising from the interventions, a situation that may in some cases result in death.

Patients with ME/CFS do not seek any special consideration; they simply wish to be treated equally to those with other classified neurological disorders. As shown in the commissioned Report that accompanies this complaint (a bound copy of which will follow), the MRC Trial clearly demonstrates that people with ME/CFS are not treated equally to those with other chronic neurological disorders.

Given the long-standing recognition that at least one of the interventions used in the trial is contra-indicated for people with ME/CFS, an intervention that is already known to have adverse effects on 50% of those who have already undertaken it, there is international concern about the MRC PACE Trial.

I urge you to read the attached Report and to respond to it with due attention and alacrity. You may wish to know that the Report is already on international academic websites.

Yours sincerely

Magical Medicine:

How to make a disease disappear

Alternative download sites:

(all files are in Adobe .pdf format)

442 pages

File size - Approx. 6Mb

<http://tinyurl.com/yega4hr>

<http://tinyurl.com/yzza82x>

<http://tinyurl.com/y9n3bll>

<http://tinyurl.com/yaevy8o>

<http://tinyurl.com/yzruptn>

<http://tinyurl.com/yjxts39>

<http://tinyurl.com/yhunue6>

<http://tinyurl.com/yjtw26x>

<http://herbiv4.wordpress.com/>

<http://magical-medicine.blogspot.com/>

19th February 2010

Letter to Sir Michael Rawlins Chairman of NICE

From Malcolm Hooper Ph.D.,B.Pharm.,C.Chem.,MRIC

Emeritus Professor of Medicinal Chemistry

View

EMAIL ADDRESSES FOR MAGICAL MEDICINE DISTRIBUTION

From Professor Hooper's letter to Sir Michael Rawlins, chairman of NICE:

"The entire report, the press release and the letter of complaint have now been circulated worldwide on the internet and have received much acclaim and support from the major ME organisations in various countries and numerous individuals, as well as academic institutions. The report is to be discussed by the International Association of CFS/ME at its next board meeting in early March, as confirmed by the President, Professor Fred Friedberg from the US."

The Magical Medicine press release, official letter of complaint to the MRC and Professor Hooper's letter to NICE were all sent to the following email addresses. If an email address is not shown then it was sent to editors/PR/managers etc with a request to forward them to the names provided. In addition, Professor Hooper sent the documents out to various people, organisations and institutions not listed here.

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The work of the College Centre for Quality Improvement (CCQI) has created a new and enhanced role for clinicians and their professional bodies in raising standards. Its national initiatives engage directly with clinicians, managers and service users and support them to take responsibility for improving local mental health services. More than 90% of mental health services in the UK participate in the work of the CCQI.

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The National Collaborating Centre for Mental Health

What is the National Collaborating Centre for Mental Health? The National Collaborating Centre for Mental Health (NCCMH) is one of seven centres established by the National Institute for Clinical Excellence (NICE) to develop guidance on the appropriate treatment and care of people with specific diseases and conditions within the NHS in England and Wales. Established in 2001, the NCCMH is responsible for developing mental health guidelines, and is a partnership between the Royal College of Psychiatrists and the British Psychological Society.

Director National Collaborating Centre for Mental Health Dr Tim Kendall

Christine Sealey Centre Manager csealey@cru.rcpsych.ac.uk

PSYCHIATRIC JOURNALS

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Editorial Coordinator, *The Psychiatrist* pb@rcpsych.ac.uk

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On the emails to ME Researchers:

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Psychiatrists

Dr Alistair Santhouse following the BMJ Editorial, to be forwarded to Professors Hotopf, David, Wessely, White and Sharpe.

ME Charities and Organisations

On the emails to ME Charities and Organisations:

“Please feel free to forward these documents to other physicians, academics, the ME community and the media as it is important to get this information widely distributed and used to good effect.”

25% ME Group

liME

MEA

AfME

CFIDS

NCF

European Alliance of ME – an alliance of ME charities from across Europe

ESME – European Society for ME

IACFS - International Association of CFS/ME

Local ME - to be sent out to all local UK ME groups

WPI – for Annette Whittmore, Dr Dan Peterson, Dr Judy Mikovits. Dr Donnica Moore

Chronic Fatigue Syndrome Advisory Committee (CFSAC) – to be sent out to all their members

HHV6A Foundation – Kristin Loomis

ME/CFS Australia – an organization like EAME, comprising 8 Australian ME/CFS charities from across the continent

ANZME – New Zealand ME national charity with local support groups across New Zealand

National ME/FM Action Network – Canadian charity with links to other ME organizations across Canada

ME Society of America

PANDORA – Patient Alliance for Neuroendocrineimmune Disorders

ME- CFS Community.com

ProHealth

National Alliance for ME US

Pheonix Rising/ aboutmecfs.org

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MEDIA

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LANCET – to several editorial staff

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