

Invest in ME Research CMO Meeting Wednesday 11th January 2017

Summary of developments following CMO's report of 2002

The ME community were by and large delighted at the contents of this report, with its strong implicit acceptance of ME/CFS as a primarily organic/biological illness. The members of the psychiatric viewpoint were sufficiently disheartened by this to refuse to sign up to the report's conclusions.

In 2004 the RCPCH (Royal College of Paediatrics and Child Health) published paediatric guidelines which were very much in line with the CMO's report.

In 2007 NICE guidelines came out, and for all the criticism of these regarding their possibly overemphasis of the merits of CBT and GET, these also cemented the concept of ME/CFS as an organic illness and made it "official".

What went wrong post 2002?

First and foremost, there was an abdication on the part of adult medicine of responsibility for this condition.

This must have been partly due to the tendency to specialisation on the part of even DGH physicians.

No specialty would accept responsibility.

In particular, the neurologists were very reluctant to be involved despite the WHO's having designated ME as a neurological disease.

The main problem was that there was no "ology" for ME, neither was one created.

This failure on the part of general medicine had a knock on effect on general practice.

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GP's sensed the reluctance of physicians to accept referrals, thus making ME less of an official disease and more of a "controversial" condition.

These factors mitigated against the positive recommendations of the above three reports/guidelines.

Secondly, and as a result of this abdication by adult medicine, when specialist ME centres were set up very few medical specialists came forward, and the only people eager to step into the vacuum were the psychiatrists. (Two exceptions to this rule were in Newcastle and St Helier, where immunologists took the lead).

There has been widespread patient dissatisfaction with most of these centres.

Firstly, the patients seldom saw an actual doctor to at least receive an official medical diagnosis.

Secondly, the only support on offer consisted of different forms of CBT and GET which patients found either ineffective or harmful depending on the variety of therapy offered.

The very existence of these specialist centres of course removed the obligation of DGH physicians and paediatricians to actually see, diagnose, help and support ME patients.

Thirdly and most importantly, the psychiatric lobby made a concerted counter-attack to recover their lost ground. This was all the more effective for being indirect. Their strategy consisted of the following

- 1) Ensuring that they were well positioned to influence medical education, both undergraduate and postgraduate.
Again they were filling a vacuum left by organic medicine.

The two major medical textbooks (The Oxford textbook of Medicine and Kumar and Clark) have chapters on ME/CFS written by psychiatrists and buried in the section on "Functional illness" or "Medically unexplained symptoms")

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Of course, the term "ME" is gradually airbrushed out of the narrative and doesn't occur in the indexes.

Likewise, the major paediatric text Forfar and Arneil had a section on CFS placed in the section on Child Psychiatry where it is stated baldly "CFS is the commonest psychosomatic illness in adolescence"

2) Use of the term "Biopsychosocial approach" as a further means of muddying the waters. (No one can object to the concept of a "biopsychosocial approach" in theory, as it is just another word for an holistic approach to any patient. However, the psychiatric lobby tend to use it excessively in their approach to ME/CFS, and then seem to forget the "bio" component!

3) Monopolising research and funding for ME/CFS for their own psychiatric agenda.

Enormous sums have been involved and large research empires have been created.

This all centres round CBT and GET, which have recently been called into question with major criticisms of the PACE trial.

Again this has all happened because of the dearth of alternative proposals from those wishing to do research aimed at biological factors.

(we should note that this, in turn, has been caused by the total lack of funding given to those biomedical research proposals which have been made – thus influencing attitudes in academia)

4) As already mentioned, the specialist centres are largely run by psychiatrists and psychologists

All this activity is carried on as if the CMO's report and NICE Guidelines did not exist, and as if there was not a growing body of evidence for biological causation of ME/CFS.

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Regarding the patient community, the psychiatric group steadfastly avert their gaze from the large number of severely affected patients, none of whom have responded to CBT or GET

The current state of affairs

- One still hears GPs saying “we don’t believe in ME in this practice”
- Adult patients have difficulty obtaining an official diagnosis of ME/CFS, and this can lead to them being deprived of benefits
- ME/CFS has effectively been downgraded from being an official medical condition to one that is unofficial and “controversial”
- There are a large number of severely affected adult patients and young people who are being neglected by the profession. Both GPs and consultants frequently refuse to do home visits on patients who are too unwell to attend surgery/outpatients.
- Most distressingly, a significant number of families of children with ME/CFS are being subjected to “Abuse by professionals” (see attached paper)
- Virtually no doctors are coming forward to establish an “ology” for ME

Final anecdote

A GP phones an ME helpline for advice.

He says “ I’m really worried I have developed ME”.

Adviser clucks sympathetically.

GP “That’s not the main problem – it’s just that I don’t know what to say to my colleagues”

Further sympathetic cluck.. “You see, it has always been a policy of our practice to treat patients with ME with unremitting hostility, ridicule and rejection.... So I can’t face telling my colleagues. I think I will just tell them I am suffering with depression”!