

## **The 'Gibson Inquiry' Report - Half Empty or Half Full?**

*John Sayer, 30th. November 2006*

I will be 54 in a few weeks, by which time I will have been suffering from severe M.E. for 14 years. I had to accept retirement (I was a high school teacher) at the age of 40, when, as tradition would have it, my life should have begun, not ended.

I welcome any attempt to improve the lives, by whatever route, of M.E. sufferers, whether it be in terms of medical, social or financial care.

When I first became ill, I was assured that I could expect to be back on my feet and working again in 2-4 years. I did expect it, but almost 14 years down the line, despite having an optimistic, positive, 'it-isn't-going-to-beat-me' attitude, it still hasn't happened. But I live in hope.

I now realise, looking back, that those attempting to reassure me 14 years ago did not understand the crucial distinction between Chronic Fatigue and Myalgic Encephalomyelitis.

When the 'Gibson Inquiry' was launched, I had mixed expectations: I did not know whether the GSRME would have any influence, would make any difference, or, indeed, would even be supportive of our case.

I was a witness to the meeting between Dr. Ian Gibson and Prof. Malcolm Hooper in 2005, which resulted in Dr. Gibson announcing that he would try for a parliamentary inquiry. I was optimistic at that point, since Prof. Hooper had made an eloquent and convincing case to Dr. Gibson for the acceptance of M.E. as a physical illness (and I thank him for that). It struck me at the time that had the whole world been able to listen in, it surely would have concluded that the psychological/physical debate was well and truly over - dead and buried forever.

I did not know whether the GSRME would be presented with the right kind of evidence on which to come to meaningful conclusions. I did not know whether the membership of the Group would be conducive to a fair examination of the evidence presented - but I was encouraged by Prof. Hooper's presentation to Dr. Gibson.

However, I was most concerned when I read the subsequent local Norfolk newspaper coverage ("Norwich Evening News") of the announcement of the proposed launch of an inquiry, which quoted Dr. Gibson as commenting, "Some say it is psychiatric and others say it is physical but it could be a bit of both."

To me, this did not bode well for a conclusion to an inquiry which would come down on the side of accepting M.E. as physical. I was hoping that, having reviewed the evidence, the Group would conclude that the case had indeed been made for accepting M.E. as such.

The Report, however, states (p26):

"It seems possible that...there is likely to be a physical element and a psychological element to the illness...For some doctors to deny the existence of a physical part of the illness is as equally unhelpful as the claim by some patient groups that there is no psychological element to the disease."

Alarmed by this, I decided that my best approach to this Report would be to go through it first to pick out what I considered to be its weaknesses, then its strengths, then come to an informed conclusion as to whether, on balance, it was helpful or unhelpful.

I embarked on this exercise still mentally and physically exhausted after producing a response to the draft NICE guidelines on 'CFS/ME' on behalf of our local M.E. support group at extremely short notice. I am aware that I may not have done as thorough a job as I would like here, but I have had to keep at it while still in the right frame of mind, otherwise I would probably not be able to pick up the momentum again.

I mention this because I would have no problem with anyone pointing out to me anything I may have missed or got wrong. I am happy for others to e-mail me on the subject, either privately (john23@sayer.abel.co.uk) or on the e-lists I subscribe to.

(A) 'Weaknesses':

p7 (1.1 Why is this report necessary?):

"At present the only treatments are symptomatic and psychosocial. For the extremely affected sufferer this is not satisfactory."

Dissatisfaction with symptomatic and psychosocial treatments is not restricted to "the extremely affected sufferer" alone: this implies that for the the majority of sufferers there is no problem with these treatments, which is not the case. This assertion calls into the question the Group's statement here that "Our task is to highlight the ongoing struggle of the CFS/ME community and *to ensure that the voice of the patient is heard.*" [emphasis added]

p7/8 (1.3 The Cost):

"No major biomedical research projects funded by the MRC have been brought to our notice."

This does not mean to say that no such projects have been undertaken, only that the Group isn't aware of any. It would have had more impact to state plainly that the MRC has not funded any major (or even minor?) biomedical research.

"In 2003 Action for ME indicated that CFS/ME may be costing the UK £3.5 billion annually in medical services, social benefits and lost incomes."

It is unfortunate that the Report repeats this claim by AfME, since it would appear that the government's response to this has not been one of being spurred into action on behalf of M.E. patients but rather of trying to reduce the cost to the nation by embarking on a programme of denying one million claimants their entitlement to incapacity benefits (Pathways To Work etc.).

p8 (1.4 Central issues):

"The Group believe that physical aspects have received less attention or support than they deserve and that this shortcoming must be addressed."

This could be construed as implying an acceptance by the Group that there *are* non-physical - i.e. psychological - aspects to M.E. (a view which is reinforced in other parts of this Report).

p8 (1.4.5):

"...some patients become depressed as a result of their illness and sometimes treatment of this depression is helpful for at least that part of their illness."

The phrase "that part of their illness" implies that depression is accepted by the Group as part of M.E.

p11 (2.3 WHO definition):

"The WHO in Geneva holds an internationally recognised classification that ME is a neurological disease. The Group feels that these definitional difficulties have only served to confuse the picture and will not be resolved unless further research is done to clarify the

nature of the disease."

The danger here is that, despite the WHO classifying M.E. as *neurological*, the Report might be seen as suggesting that this classification is now open to question: "unless further research is done to *clarify the nature of the disease*." [emphasis added]

p11 (2.4. Teenagers and Children):

"...the Group accepts that CFS/ME is prevalent amongst teenagers and possibly in children. However it is very unlikely to occur in infants and young children and so should not be confused with Munchausen by proxy for example."

This seems to be saying (a) that "Munchausen by proxy" exists and (b) that it can often be mistaken for M.E. in infants and young children. If so, this is highly alarming and destructive.

p12 (2.5.1 Kumar and Clark Endorsed by the BMA):

"While CFS/ME remains only in the Psychological section of medical discourse, there can be little chance of progress."

The use of the word "only" here would seem to imply that the Group believes 'CFS/ME' should be classed as *both* psychological and physical.

"The Group was interested by the concept of a 'biopsychosocial' model of illness as long as one aspect is not given particular prevalence over the other, both approaches must be considered at the same time."

By "both approaches" one assumes is meant (a) the biopsychosocial model and (b) the biomedical model. If this is the case, then what the Report seems to be saying here is that *both models have equal validity* (a point reinforced elsewhere).

p19 (3.1. The Oral Hearings):

"The overwhelming message from all of our speakers was that more money was needed to develop knowledge in this contentious area."

It is interesting to note the use of the word "contentious" here, especially for those who are already satisfied that the psychological/physical debate has been resolved by overwhelming evidence for M.E. being wholly physical. It is no surprise that the 'psychologisers' are calling for more money to fund their own research.

Prominence is given to comments from Prof. Peter White ('psychologiser'), e.g. "...ring fence some money and the scientists will follow."

"Scientists" would, of course, include psychologists and psychiatrists.

p20 (3.2 Other Evidence We Received):

"Professor [Simon] Wessely is considered by many to be the leading expert on treating CFS/ME and the CFS/ME treatment centres set up by the NHS have been to his model."

This phrase appears to be an acknowledgement and endorsement of Prof. Wessely as "the leading expert" on M.E. Its use would be redundant otherwise. Yet it *has* been deliberately used. The concept of Prof. Wessely as "leading expert" is reinforced in the next paragraph by the comment: "The Group were disappointed not to have the opportunity to discuss this important issue with such a key figure."

"Many patient groups oppose these treatments because...they are psychologically based."

The use of the phrase "many patient groups" instead of, say, "many M.E. patients and advocates" is significant here in light of the reference three sentences later to "extreme harassment he [Prof. Wessely] received from a very small fringe section of the M.E. community": the Group appears to believe that that "patient groups" do not necessarily represent the views of M.E. patients in general - that the 'broad church' of the 'M.E. community' contains 'fringe' elements, who perhaps should not be taken seriously.

(pp20/21):

Reference is made to the work in the fields of cardiology, brain activity/scans and viral effects of Drs. Paul Cheney, Byron Hyde and John Richardson, but the impact of their findings is somewhat diluted by the qualifying phrases "this work has yet to be published, "these observations await confirmation", "others have yet to confirm or refute these observations" and "the NICE draft guidelines make little reference to the possibility of viral investigation in ME patients".

"The Group recommends, firstly, that these studies and other others like them must be examined by an independent scientific advisory committee...Secondly, many of the studies we received were conducted on a very limited scale and their findings need to be confirmed or *refuted* by large-scale investigation. Until this happens, the field will remain confused." [emphasis added]

This indicates that the Group is not convinced by the research referred to and is, despite the presentations and submissions made to the Inquiry, still of the opinion that the issue of the psychological/physical debate remains confused, which will come as a disappointment to those who at least hoped, if not expected, that the Inquiry would conclude that biomedical evidence has already settled the debate.

p21 (3.3. Potential Causes of CFS/ME):

"Fatigue is very common."

This is an unfortunate opening sentence for this section, echoing as it does what is perceived by M.E. patients to be a mantra of the 'psychologists' - namely that the cardinal feature/main symptom/characteristic hallmark of M.E. is 'fatigue', when M.E. patients, at least, know that it isn't.

(p22):

Reference is made to a number of biomedical investigations (MRI scans, spinal inflammatory changes etc.) but their findings, once again, are tempered by the comment:

"Unfortunately none of these changes have yet been proven to be specific for the disease since similar findings are detected in other conditions and it is not yet possible to determine whether these changes are the result of the disorder or are its cause."

p22 (3.3.1 Lyme Borreliosis):

The Report states that "while those with Lyme Borreliosis exhibit many similar symptoms to CFS/ME the Group believes they are two separate afflictions", but without stating any reason for this conclusion, other than giving a mention of unspecified "discussions with the Health Protection Agency".

pp22/23 (3.3.2 Other Viruses):

The Report states, "Viruses are areas which need further research", continuing, "It is clear that fatigue is a much recorded post-viral symptom" but cautioning that "there is not

enough evidence to determine whether post-viral CFS/ME is a separate illness from CFS/ME."

This last sentence implies the Group's belief that there may be a number of versions of 'CFS/ME', identified by their respective triggers - as well as a (*the?*) version which has *no* identifiable trigger.

p23 (3.3.3. Organophosphates):

"The symptoms associated with the chronic effects of exposure to OP's are very similar to those for CFS/ME."

In other words, the Group believes that organophosphate poisoning and M.E. are (as with Lyme Borreliosis) separate afflictions.

p23 (3.3.4 Vaccinations):

"The Group found that there is no strong evidence to link CFS/ME to vaccination and it is unlikely to be a cause."

This statement will come as a major surprise to those who have written papers on the links between M.E. and vaccinations and those patients who can accurately pinpoint the onset of their illness as immediately following a vaccination.

p24 (4.2. Existing Treatments):

The Group states its position clearly:

"Psychosocial methods of treatment *do have a role to play* as the relation between mind and body in disease is complex." [emphasis added]

p24 (4.3 Cognitive Behavioural Therapy):

The Report states categorically (echoing the current NICE draft guidelines):

"The most effective psychological therapy, which has been shown as such in controlled clinical trials, is Cognitive Behaviour Therapy (CBT)."

Prominence is given here to one of the two (out of six) presenters at the Oral Hearings sent in his place by Prof. Simon Wessely:

"Prof Trudie Chandler [sic] presented to the group on this treatment. Prof Chandler's results were impressive. This treatment certainly has a role to play in treating CFS/ME...in CFS/ME this, and GET...are the only available treatments which have been shown to be effective in several controlled trials."

Noting that "Prof Chandler suggested that CBT has a biological effect on the body" (which is a claim for mind-over-matter), the Report states, "The Group would like to see further research into what this effect is as it may open avenues of investigation into biomedical causes."

This last sentence has far-reaching implications: the Group is apparently willing to accept that *thoughts* can actually cause biological changes and that, further, this validates research into the claim by some (i.e. the 'psychologists' and other New Age 'gurus') that M.E. is *caused by thoughts*.

pp24/25 (4.4. Graded Exercise Therapy):

At first glance the Group's comments on GET seem to be expressing misgivings and advising caution about its worth as a treatment for M.E., but this must be taken in the context of the earlier remark (p24) that "this [CBT] and GET...are the only available treatments which have been shown to be effective in several controlled trials."

p25 (4.5 Pacing):

The definition of pacing given by the Report is one that M.E. patients might not recognise:

"As the name suggests the patients pace themselves. They only move around or undertake activities to the extent that they are comfortable, *the idea being that they will not fully exert themselves if they do this.*" [emphasis added]

The common understanding of pacing, however, is that it entails the 'spreading out' of exertion/activity in order to prevent as much as is realistically possible the exacerbation of symptoms and/or relapses - in the same way (and for the same reason of avoiding 'burnout') as long-distance runners pace themselves. (The ultimate goal is the same: optimum achievement.)

p25 (4.6 A Holistic Approach):

"[The] observation that GET may make severe sufferers feel worse has lent fuel to their often serious antipathy to the doctors offering it. Some of our evidence suggests that GET carries some risk and patients should be advised of this."

It is not only "severe sufferers" who can be made worse by GET. Indeed, patient testimony reveals that many *become* severely affected as the direct result of GET.

(p26):

It will be disheartening to many that the Group appears to hold the view that M.E. is part-physical and part-psychological:

"It seems probable that...there is likely to be a physical element and a psychological element to the illness. Therefore successful treatment pays attention 'holistically' to the whole person, caring for the mind and body. For some doctors to deny the existence of a physical part of the illness is *as equally unhelpful* as the claim by some patient groups that there is no psychological element to the disease." [emphasis added]

It is interesting to note that here again emphasis is placed on the alleged views of "patient groups" only, with no reference to patients as individuals with their own views, or to the findings of scientific researchers.

p26 (4.7 Other Treatments):

Curiously, the Report refers here to antibiotics, antivirals and anti-inflammatory agents as examples of "unorthodox therapies", remarking later (4.7.4) that "The group was intrigued but sceptical about the claims of therapeutic success for unorthodox methods of treatment", while, however, stating (4.7.1) that analgesics and *anti-inflammatory agents* may provide some pain relief as they can act on the myalgia." [emphasis added]

p28 (5.1 Treatment Centres):

The Report does not indicate awareness of the general antipathy towards the 'CFS/ME centres', as expressed, for example, in recent communications from RiME - antipathy based on the experience of patients faced with little more than CBT and GET at these centres:

"The Group is extremely pleased with the advent of these centres and we hope they will be

maintained and indeed rolled out."

pp28/29 (5.2 Research Issues):

Criticism of the Medical Research Council is noteworthy here, pointing out, for example, that the MRC "has funded five applications relating to CFS/ME, mostly in the psychiatric/psychosocial domain", but (again) tempering this observation with the comment: "These are to be welcomed of course since they are largely concerned with efforts to confirm or refute the nature of different forms of therapy in carefully controlled trials" - a view which many will see as naive wishful thinking, convinced as they are themselves that exercises such as the PACE and FINE trials are merely propagandic and contrived justifications for the implementation of CBT and GET in the 'CFS/ME centres'.

p33 (7.1 The Group's Response):

"There is a great deal of frustration amongst the CFS/ME community that the progress made in the late 1980s and early 1990s toward regarding CFS/ME as a physical illness has been marginalised by the psychological school of thought."

It has to be said, however, that even parts of this Report itself lend support to "the psychological school of thought":

"The Group was interested by the concept of a 'biopsychosocial' model of illness as long as one aspect is not given particular prevalence over the other, both approaches must be considered at the same time." (p12, 2.5.1)

"Psychosocial methods of treatment do have a role to play as the relation between mind and body in disease is complex." (p24, 4.2)

"The most effective psychological therapy, which has been shown as such in controlled clinical trials, is Cognitive Behaviour Therapy (CBT)." (p24, 4.3)

"Prof Trudie Chandler presented to the group on this treatment [CBT]. Prof Chandler's results were impressive. This treatment certainly has a role to play in treating CFS/ME. Although in other illnesses this treatment is provided as an adjunct to treatment for the organic disease, in CFS/ME this, and GET...are the only available treatments which have been shown to be effective in several controlled trials." (p24, 4.3)

"It seems probable that, as with most other diseases, there is likely to be a physical element and a psychological element to the illness...For some doctors to deny the existence of a physical part of the illness is as equally unhelpful as the claim by some patient groups that there is no psychological element to the disease." (p26, 4.6)

p33 (7.2 Areas for Further Examination):

"Why does the DOH not keep or collect data pertaining to the number of CFS/ME sufferers in the UK?"

A very good question, but it is regrettable that the Report does not pose the obvious secondary question here: Without numbers, how can the setting up of 'CFS/ME centres' be justified or national and local funding calculated?

"No representative who appeared at the Oral Hearings proposed CFS/ME was entirely psychosocial. So why has this model taken such a prominent role in the UK?"

The Report answers this question itself, at 6.1 and 6.3 respectively:

"At present ME/CFS is defined as a psychosocial illness by the Department for Work and Pensions (DWP) and medical insurance companies."

"There have been numerous cases where advisors to the DWP have also had consultancy roles in medical insurance companies. Particularly the Company UNUMProvident. Given the vested interest private medical insurance companies have in ensuring CFS/ME remain classified as a psychosocial illness there is blatant conflict of interest here."

(B) 'Strengths':

p7 (1.1 Why is this report necessary?):

"...some of the CMO Report's recommendations for further research have been ignored."

(Unfortunately, however, these recommendations are not identified.)

p9 (1.4.7 Central Issues):

"More research into possible causes and treatments is vital."

The 'M.E. community' regards this, and all similar statements in the Report, to be self-evident.

p10 (2.2 ME Sufferers Bill, 1988):

"In Britain, there has been a clear historical bias towards research into the psychosocial explanations of CFS/ME. This is despite Parliament recognising ME as a physical illness in a Private Members Bill, the ME Sufferers Bill, in 1988."

This is an important point to highlight.

p10 (2.3 WHO Definition):

"There is commonly held belief circulating that the World Health Organisation (WHO) categorises CFS/ME under both neurology (i.e. disorders of the nervous system) and neurasthenia (mental and behavioural disorders or other neurotic disorders). Indeed this is reported in medical textbooks. The Group found this assertion to be incorrect."

These are important points to highlight.

p12 (2.5.2 The Oxford Criteria):

"The Oxford Criteria first published in 1991 is that generally used in the UK to diagnose persons with CFS/ME for research purposes. However due to the general nature of this guideline it is possible that patients with a spectrum of fatigue symptoms whom are unlikely to have authentic CFS/ME will be included in research."

These are important points to highlight.

(p13):

"The Group found that the international criteria paid far greater attention to the symptoms of CFS/ME while the Oxford Criteria focus very little on any symptoms other than long term tiredness. There is concern that the broad spectrum of patients who may be included in these criteria may lead to inaccurate results in patient studies of CFS/ME. The Group feels that there is room for a further review of the criteria which should be updated, in light of the peer reviewed and evidence based research done both internationally and in the UK in the past 15 years."

These are important points to highlight.

p14 (2.6 Other Criteria):

"In Canada, Dr Bruce Carruthers and his research team have developed a Diagnostic Protocol for CFS/ME. The Group found that these criteria were much more detailed, including many more symptoms of CFS/ME compared with the Oxford Criteria. Their exclusions are useful as they begin to extrapolate an idea of CFS/ME separate from other related or similar illnesses."

It is gratifying that the Canadian Guidelines are given prominence here. These are important points to highlight.

p19 (3.0 The Science - Symptoms and Potential Causes):

"The Group calls for a further Inquiry into the Scientific Evidence for CFS/ME by the appropriately qualified professionals. This Inquiry should be commissioned by government undertaken by an independent panel of scientific and medical experts, including virologists, immunologists, biochemists etc who can objectively assess the relevance and importance of the international scientific data."

A call for a further Inquiry is welcome - but it is unclear who "appropriately qualified professionals" might be.

p19 (3.1):

"There are innumerable potential causes and unusual symptoms found in CFS/ME patients, but in the UK at least, sufficient research has not been done to verify any one cause. The Group feels the necessary research must be funded immediately."

The call for immediate funding is to be commended, although it might have been better to have referred to "possible causes" rather than "any one cause" (which is restrictive).

p25 (4.4 Graded Exercise Therapy):

"Given the evidence from patients and Dr White the Group is concerned that the NICE guidelines are recommending these treatments without caveats. We heard suggestions that there is a risk of heart trouble in patients with CFS/ME. This has serious implications for GET. As such the group would recommend that the heart function is examined, especially in the severely affected, before GET is recommended."

These warnings concerning the NICE guidelines and potential heart problems are to be commended - but those not labelled "severely affected" are *also* at risk.

p28 (5.2 Research Issues):

"Provision of resources for biomedical research is urgently needed."

Although self-evident to the 'M.E. community', this statement is to be commended, as is:

"The MRC should do more to encourage applications for funding into biomedical models of ME."

p30 (6.1 Patient Experiences):

"At present ME/CFS is defined as a psychosocial illness by the Department for Work and Pensions (DWP) and medical insurance companies. Therefore claimants are not entitled to the higher level of benefit payments. We recognise that if ME/CFS remains as one illness

and/or both remain defined as psychosocial then it would be in the financial interest of both the DWP and the medical insurance companies."

The raising of this issue is to be commended.

p31 (6.2 What The Government Says):

"The DWP is reliant on medical opinion when determining benefit entitlement for DLA. Until medical opinion is better informed as to the nature of this illness ME sufferers will have to live with the double burden of fighting for their health and their benefits."

The raising of this issue is to be commended.

p31 (6.3 How the Department for Work and Pensions Formulates CFS/ME Policy):

"...government looks like adopting a new benefits policy which may still leave it discriminating against claimants with ME/CFS."

The raising of this issue is to be commended, as is pointing out that

"Given the vested interest private medical insurance companies have in ensuring CFS/ME remain classified as a psychosocial illness there is blatant conflict of interest here."

pp33/34 (7.2 Areas for Further Examination):

The list of 13 "Areas for Further Examination" is to be commended but, it has to be said, consists of what the 'M.E. community' itself has been demanding for decades.

p35 (7.3 The Immediate Future):

What the Report calls for is summed up in its final paragraph:

"This group believes that the MRC should be more open-minded in their evaluation of proposals for biomedical research into CFS/ME and that, in order to overcome the perception of bias in their decisions, they should assign at least an equivalent amount of funding (£11 million) to biomedical research as they have done to psychosocial research. It can no longer be left in a state of flux and these patients or potential patients should expect a resolution of the problems which only an intense research programme can help resolve."

The concern and perception of the 'M.E. community' is not so much that the MRC has not been "open-minded" enough in its attitude, but that it is being *deliberately and flagrantly discriminatory* where biomedical research into M.E. is concerned, and it would be preferable for this to have been stated boldly and unequivocally here.

The call for an amount of spending on biomedical research equal to that already spent on psychosocial research is to be welcomed, but since this gives the impression of granting equal status to the psychosocial and biomedical models, perhaps a call for *at least twice* the amount (i.e.£22 million) to now be allocated to biomedical research would have had more impact.

(C) 'Synthesis':

How does one summarise this Report, and by what criteria?

The obvious and first criteria to be considered are the Terms of Reference of the Inquiry itself

(From the GSRME's press release, December 2005):

"The Group on Scientific Research into M.E. has been established to assess the progress of scientific research on M.E., since the publication of the Chief Medical Officer's Working Group Report into CFS/ME in 2002. In particular the group has been established to:

- increase public understanding of scientific research into ME/CFS
- evaluate progress in the development of a full programme of research into ME/CFS
- identify research and funding requirements in establishing the cause of ME/CFS"

(a) There is no evidence (as yet, anyway) that the GSRME has been able to "increase public understanding of scientific research into ME/CFS". Unfortunately, as far as I am aware at the time of writing, there has been no national coverage of the Report's release, only local media publicity in Norfolk (Dr. Gibson is MP for Norwich North).

(b) By a "full programme of research into ME/CFS" I presume is meant literally that - a *full* programme. We know, however, that virtually all official research in the UK has been either biopsychosocial or psychosocial, and without at least equal biomedical research there can be no meaningful talk of a "full programme of research", thus making it impossible to "evaluate progress in the development" of one - except to say that it doesn't exist.

(c) References to identifying "research and funding requirements in establishing the cause of ME/CFS" in the Report are:

"There are innumerable potential causes and unusual symptoms found in CFS/ME patients, but in the UK at least, sufficient research has not been done to verify any one cause. The Group feels the necessary research must be funded immediately." (p19, 3.1)

"Changes in MRI scans of the brain and in the endocrine system are also reported but again their specificity for CFS/ME is unproven and whether they result from the illness or are involved in its cause requires much further work. Inflammatory changes in the spinal cord found in a small number of post mortem specimens also points to the need for more research." (p22, 3.3)

"Future research therefore needs to focus on efforts to categorise the illness or illnesses and on possible infective or other precipitating causes and into the factors contributing to a person's predisposition to the disease." (p22, 3.3)

"The Group found that there is no strong evidence to link CFS/ME to vaccination and it is unlikely to be a cause. However this is a possible area for further investigation." (p23, 3.3.4)

"Prof. Chandler [sic] suggested that CBT has a biological effect on the body. The Group would like to see further research into what this effect is as it may open avenues of investigation into biological causes." (p24, 4.3)

"The MRC should do more to encourage applications for funding into biomedical models of ME." (p28, 5.2)

"...it is important for the MRC to be seen to be balancing this [psychiatric/psychosocial oriented research] with support for more high quality basic research into potential causes." (p29, 5.2)

"The Group calls for a further Inquiry into the Scientific Evidence for ME/CFS by the appropriately qualified professionals." (p32, 7.1)

"The Group believes the UK should take this opportunity to lead the way in encouraging biomedical research into potential causes of CFS/ME." (p33, 7.1)

To summarise, therefore, with regard to (c) above, in terms of seeking to "identify research and funding requirements in establishing the cause of ME/CFS", the Group considers that more research is needed on:

changes in MRI scans of the brain and in the endocrine system,  
inflammatory changes in the spinal cord,  
categorising the illness or illnesses,

possible infective or other precipitating causes,  
factors contributing to predisposition to M.E.,  
*possible* links with vaccination,  
possible *mental* causation,  
the scientific evidence for M.E., and  
biomedical research into potential causes,  
along with immediate funding for the search for a single cause.

So only one of the three Terms of Reference has actually been met by the Report (although increasing public understanding of the scientific research may yet follow).

Where does this leave us?

In a nutshell, the Report asks for more biomedical research, *but*, it must be remembered, because the GSRME is clearly not convinced by the biomedical evidence we have already and wants it checked: "...many of the studies we received were conducted on a very limited scale and their findings need to be confirmed or refuted by large-scale investigation. Until this happens, the field will remain confused." (p21, 3.2)

I used the metaphor of the half empty/half full glass in the title of this review because whether this Report is considered helpful or unhelpful depends on what can be gleaned from it, and by whom. The "target audience" is not specified, but in reality it is anyone with an interest in M.E., from the government down to the patient.

As a patient, what I get from it is the hope that the Report's very existence will focus attention on the need for official recognition of the international biomedical research and findings *that already exist* and the unacceptable discrimination and abuse that M.E. sufferers *still* face.

But what horrifies me is that the Report reinforces the contention that M.E. is a predominantly psychological problem - the one aspect that I fear will overshadow other crucial points raised in the Report - and a serious concern is that those who currently have influence over policy-making (in the NHS, DWP, DoH etc.) will seize on those parts of the report which suit their own agendas [emphases added]:

"The Group was interested by the concept of a 'biopsychosocial' model of illness as long as one aspect is not given particular prevalence over the other, *both approaches* must be considered at the same time." (p12)

"Psychosocial methods of treatment *do have a role to play* as the relation between mind and body in disease is complex." (p24)

"The most effective *psychological therapy*, which has been shown as such in controlled clinical trials, is Cognitive Behaviour Therapy (CBT)." (p24)

"Prof. Chandler's results were impressive. *This treatment [CBT] certainly has a role to play in treating CFS/ME...*in CFS/ME this, and GET...are the only available treatments which *have been shown to be effective* in several controlled trials." (p24)

"Prof Chandler suggested that *CBT has a biological effect on the body*. The Group would like to see further research into what this effect is as it may open *avenues of investigation into biomedical causes*." (p24)

"It seems probable that, as with most other diseases, there is likely to be a physical element *and a psychological element* to the illness...For some doctors to deny the existence of a physical part of the illness is *as equally unhelpful* as the claim by some patient groups that there is no psychological element to the disease." (p26)

In conclusion, therefore, I'm afraid I have to say that as an M.E. sufferer, although I appreciate the GSRME putting so much time and work into this Inquiry and Report, for me personally the glass is half empty - and draining.