

**A SCIENTIFIC REVIEW OF MULTIPLE CHEMICAL SENSITIVITY:
IDENTIFYING KEY RESEARCH NEEDS**

Working Draft Report

November 2008

I wish to comment on the above report as a sufferer of MCS and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). The comments are based on my experience, communication with other sufferers and my reading on these subjects. I also wish to bring a valuable reference to your attention.

It is pleasing to see that the Government is attending to this important problem. However, the report may have been more complete and balanced had you taken into account more of the work of Dr Martin Pall, namely his book,

Explaining “Unexplained Illnesses” Disease Paradigm for Chronic Fatigue Syndrome, Multiple Chemical Sensitivity, Fibromyalgia, Post-Traumatic Stress Disorder, Gulf War Syndrome, and Others:

(Martin L Pall; Haworth Press, 2007).

Chapter 7, ‘Multiple Chemical Sensitivity’ and chapter 13 ‘What About Those Who Say It Is All In Your Head?’ are particularly relevant to your report.

In the above chapters Dr Pall argues for the physical basis of MCS, providing evidence, some of which is reflected in your report. Dr Pall also proposes a common mechanism for MCS and several other conditions such as Chronic Fatigue Syndrome which is commonly associated with MCS, and for PTSD, etc. The psychogenic advocates (Dr Pall’s term), whose work is much quoted in your report, do not appear to have acknowledged this proposal. I would recommend it for your consideration.

A second point not considered by your report is that in the experience of patients the onset of MCS is sometimes preceded by infection. I cannot provide a specific reference apart from Dr Pall's book which proposes connections between many types of trauma including infection, through the nitric oxide mechanism.

No doubt you are already aware of the most recent report on Gulf War Illness and its conclusions in relation to the impact of chemicals on health and the recent decision of a court in the UK relating to the use of pesticides and the Government's method of determining their impact.

<http://www.medpagetoday.com:80/PublicHealthPolicy/MilitaryMedicine/8671>

<http://www.pesticidescampaign.co.uk/documents/PRESS%20RELEASE%20-%20DEFRA%20to%20appeal%20High%20Court%20ruling.pdf> respectively.

I believe your report is overly swayed by the 'psychological disposition' theory. You make the important statement: 'The scientific weight-of-evidence currently suggests that while physiological mechanisms *may* play a part in MCS, there *is* also a psychological or psychogenic component in its pathogenesis. Recent medical/scientific *opinion* suggests that MCS has a multifactorial origin,...' (my italics) (p 31). In this statement opinion is being treated as fact, suggesting that evidence for psychological factors overrides the evidence for physical factors.

Psychogenic advocates have trouble accepting that the bodies of susceptible individuals can be disturbed by the environment in ways that are not yet understood. The reasoning seems to be, 'if you can't find an immediate biological mechanism for a condition, it must be psychological' or, when lip-service is being paid to the biological aspects, the condition is called 'biopsychosocial' or 'multifactorial'. Working backwards, 'if you have this condition, there must be something psychologically wrong with you' is the diagnosis. The same kind of reasoning is applied by the same school of thought to ME/CFS. This is diagnosis by default. The diagnosis of somatisation itself needs to be questioned since it is abandoned once a physical cause for symptoms is found. Surely, there are lessons offered by the history of Multiple Sclerosis, stomach ulcers, etc. but these lessons have not been learned. As one doctor has said: 'In medicine we have a bad habit. If a doctor cannot figure out what is wrong with a patient, the doctor brands the patient a turkey.'

It is not denied that psychology can have a role in illness but the psychogenic advocates fail to consider the possibility that psychological pathologies can be caused by physical

and genetic susceptibilities. As Dr Pall says, ‘Genes may, of course, influence psychology as well as biology, but when they do, they do so via the biology.’ (p 207) Anecdotal evidence also shows that the symptoms of people with MCS improve without psychological intervention when their general health improves. This needs to be further investigated.

I make the recommendation that research is concentrated on the following basic issues which are of utmost importance to both sufferers and the medical profession in relation to MCS:

- The discovery of a biological marker
- Effective treatment which at least alleviates the condition
- Prevention

It is difficult to see how proposals to research psychological mechanisms, somatisation etc. add to these aims. What can speculations on psychogenic causation contribute to a solution for MCS? Even if we were to accept a causal relationship between MCS and past trauma, anxiety, depression, etc. it is impossible to prevent these from occurring in people’s lives. Imbedded in the theories of psychological causation is the suggestion that treatment of these conditions will cure/alleviate MCS. Yet, the treatment record of these conditions is poor. There is even less chance that psychological treatments will help MCS which is supposedly superimposed on psychological problems.

Secondly, psychological conditions are not in themselves MCS and most people with these conditions do not get MCS. What of the people with no prior psychological illness who do get MCS? In practice, the attention being given to possible past psychological conditions (which are mostly diagnosed retrospectively) diverts attention from the current anxiety and depression which sufferers often experience as a result of chemical exposure and having their condition invalidated by health professionals.

Interposing a psychological mechanism into the acquisition and continuation of MCS does not help to explain why most people with past psychological trauma, etc, do not get MCS. We are then still left with the need for a detailed explanatory mechanism.

Psychological theories in this area are even more difficult to test than the physical and lend themselves to even more equivocal interpretations. Results of experiments from which psychological interpretations are drawn often lend themselves to alternative, physically based, explanations. It is of concern that these kinds of studies can lead to the condition being misinterpreted as 'just' psychological and amenable to talk therapies, as is being done already by some practitioners.

In the interests of parsimony and in view of the shortage of resources research approaches need to cut to the chase and investigate the particular physical factors which differentiate MCS, leaving aside the virtually untestable psychological constructs.

The assumptions, methods and conclusions of experiments and studies of MCS need to be rigorously examined. The claims being made also contradict my experience and of other MCS sufferers in many respects.

- The symptoms of MCS are often treated dismissively as merely subjective and not observable. I have several symptoms in response to chemicals which could be observed: thumping heart or arrhythmias, sweating, shallow breathing or difficulty breathing, 'burnt' or inflamed airways followed by hoarseness for days in the wake of some exposures. I know what caused these symptoms because they were immediate. Of course, the symptoms need to be 'caught' at the time. Importantly, the experimenter must not invent some other explanation for the symptom such as anxiety, dismissing exposure as the physical cause. Very serious sufferers of MCS may get anaphylactic shock which does not seem to be considered by the sceptics of physical causation.
- Several beliefs are attributed to sufferers of MCS. One of these is that these people have lived in expectation of their symptoms. There are also suggestions that MCS sufferers have lived in fear of a harmful environment. This fear seems to be retrospectively diagnosed. Yet, MCS would have been unimaginable to most people before onset. I was ambushed by reactions to substances which had never been a problem to me before. When my workplace moved to a new office I reacted to the dust from the veneer and chipboard desks by choking and with breathing difficulties. I recall no discernible odour. (This incident also signalled the onset of my ME/CFS.) Much later, upon entry into a Thai restaurant and later again upon entry to a beauty salon filled with acetone fumes, I suffered differing and immediate symptoms. Over time, sudden, unexpected ambushes occurred many times in reaction to numerous different substances. Each time it was a bewildering shock and surprise. None of these attacks were preceded by any unpleasant or 'stressful circumstances' as suggested in your report (p 30).

Like most people, I never lived in anticipation of an MCS experience or worried about possible environmental toxins. However, I did become interested in the issue after the onset of MCS. Until then I had never heard of MCS and had no name for it for some years. The psychogenic advocates need to differentiate between antecedent and consequence. No physician encouraged me or could make any sense of my symptoms. Most people with this condition get little sympathy from the medical profession so it is hard to see how it can be called an iatrogenic condition. I did not think of myself as sensitive in this way and between events I forgot these reactions until the next unanticipated attack. This did not prevent an ambush by yet another substance. While it is easy to see how anxiety can worsen the experience, positive thinking, relaxation, self-talk etc. in no way interrupt or assist in avoiding the symptoms.

- Many of the experimenters on MCS are subject to confirmation bias; they test their hypotheses assuming that MCS sufferers will react because they expect to react. The experimenters ought to test the converse expectation also – that an MCS person can become conditioned to expecting that a substance is safe and still have an adverse reaction. For example, I had long used a soap which was safe for me until one day, handling a new bar of the soap I immediately got arrhythmias. Upon subsequent inspection after this reaction I noted that the soap had a different colour and its composition appeared to have been changed. There was no discernible change in odour. Another sufferer noted changes in this soap but without the same drastic reaction. I have many examples of having my positive expectations of safety disappointed.

Using the expectation/conditioning theory, it could be argued that Daniel Hurley, the English boy who died as a result of using a spray deodorant, had been conditioned to this substance in a positive way. His sensitivity, considered a psychological symptom in others, translated into a fatal event.

<http://au.news.yahoo.com:80/a/-/newshome/5163967>

Another example of the confirmation bias of psychogenic advocates is the way they seem ready to believe patients' self-reports of past trauma, anxiety and depression but they have trouble believing patients' reports of suffering from physical symptoms due to exposure in the present.

- Some researchers need to overcome certain preconceptions about the details of MCS. They refer dismissively to the condition as a mistaken reaction to 'harmless' chemicals. This is an assumption. Peanuts are also harmless for most

people but fatal to others. They ignore the fact that the effects of most chemicals which are widely used have not been investigated one at a time, let alone in combination, which is how they are experienced in everyday life.

The level of sensitivity and its variability in MCS people seems beyond their imagination. Hence, they make assumptions in trials about placebos and masking agents and what an MCS patient will be sensitive to or not. The questions is: when an odour has been 'masked' presumably by another chemical, is the chemical presented to the subject the same as the unmasked one? Is Opium perfume the same thing when the scent has been 'masked' or removed? (I am not sure if this is possible.) A substance which passes for a masking agent or a placebo to the experimenter may be perceived as just another sensitivity-inducing chemical by the subject. No wonder the results of various experiments are conflicting. Much attention is also paid to odours. Dr Pall concludes that odours are not the major aspect of MCS and besides, people whose olfactory function is disabled can also have MCS (p 132-33).

While the psychogenic advocates claim to aim for 'a more integrated and dynamic understanding of illness in general, beyond the restrictive body-mind dichotomy' (p 27 of your report) it is these advocates who create the dichotomy by ignoring the detailed physical evidence pointing to physical causation, preferring the 'unexplained' illness model into which they insert their psychological causation beliefs. Their 'theories' are no more than favoured explanations grafted onto a phenomenon. For example, have they debated the role of genes in this condition? Dr Pall says 'So, how do the psychogenic or malingering advocates deal with the genetic studies of these multisystem illnesses? They ignore their existence.' (p 207)

Your acceptance of many claims of the psychogenic advocates at face value, and the recommendations based on these claims undermines the impartiality of your report. I hope you will take the above issues and Dr Pall's discussions into account in your final report. It is also hoped that the importance of theories and evidence of physical causation are given full weight in your report and recommended research.

SUPPLEMENTARY SUBMISSION TO WORKING DRAFT REPORT ON MULTIPLE CHEMICAL SENSITIVITY

Would you please accept the following additional references to my submission of 26 Dec 2008:

(i) Psychogenic Origins of Multiple Chemical Sensitivity Syndrome: A Critical Review of the Research Literature. Ann L Davidoff & Linda Fogarty.

Archives of Environmental Health 1994;49:5:316-325

(ii) Multiple Chemical Sensitivity: A 1999 Consensus. Archives of Environmental Health: 1999;54:3:147-149 (In this Consensus 34 prominent experts on Chronic Fatigue Syndrome such as Dr Leonard Jason and Aristo Vodjani, with Charles Lapp provided hard evidence that this illness can be chemically induced as well as virally induced).