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December 14, 2008

MCS Report
NICNAS (&OCS)
National Industrial Chemicals Notification
& Assessment Scheme
(& Office of Chemical Safety)
Australian Department of Health & Ageing
G.P.O. Box 58
Sydney N.S.W. 2001

Comment on MCS Report:

Scientific references should refer to each paragraph or comment in the review, especially as the MCS report aims to have a 'broad coverage of all available scientific literature and technical information'.

Scientific references should include these two books. Both are well-referenced and outstanding.

Rea WJ. 'Chemical Sensitivity, Volumes 1-4; 2924 pages. Boca Raton: Lewis Publishers: 1992 - 1997.

Pall ML. 'Explaining 'Unexplained Illnesses': Disease Paradigm for Chronic Fatigue Syndrome, Multiple Chemical Sensitivity, Fibromyalgia, Post Traumatic Stress Disorder... and others'. New York; Haworth Press: 2007.

Dr Rea provides 'a clinical perspective... from observing or treating over 20,000 environmentally sensitive patients' (forward by Prof Ashford). Volume 4 'explains diagnostic and treatment practices that have been successfully used' (Preface to Volume 4).
Back Cover of Volume 4: 'information... from the treatment & study of an estimated 100,000 patients by other environmentally oriented physicians and scientists around the world' supplements ' the studies at EHC'.
Dr Rea has recently focused on chemical sensitivity, and has also served as a cardiovascular surgeon, chief of thoracic surgery, and adjunct professor of psychology.
I've heard Australian medical practioners with MCS patients mention Dr Rea's work on chemical sensitivity with much respect.

Professor Martin 'Pall has integrated a massive amount of molecular/ biochemical data' (SA Levine, PhD. President... Allergy Research Group.) From the back cover.

Dr Grace Ziem states that 'Dr Pall has put together an insightful and detailed view of... inflammatory biochemistry... that makes important contributions toward science-based treatment' (Review in Pall's book).

Aetiology, diagnosis, modes of action and current treatment of MCS are fully outlined in the work of Rea and Pall. I have found their suggestions most helpful with my own health.
Reduction of overload of pollutants, biochemistry, and nutritional supplementation are stressed by both Rea and Pall.

The above three elements can be supported by the Australian government.

'The Scope of the (MCS) Study... examines... treatment... and clinical management strategies'.

Checking nutrient levels of patients, then encouraging optimal levels of nutrient pools by providing low-allergy nutrient supplements (in optional high doses) is to be recommended. The funding for tests and supplements should be supported by the Australian government.
Many MCS patients would therefore benefit from this clinical management, together with 'reduction of overload of pollutants' (see Rea's Vol 4, p2285).

Comment on 3.2 proposed models, paragraph 6
Are 'MCS patients... able to discriminate in double-blind placebo controlled challenge studies (using an olfactory masking agent) between reported environmental triggers and placebos'?

Is the olfactory masking agent a chemical, even though sensitivity to chemicals is being researched? What is that masking agent?
Are the studies of Staudenmayer and Das-Munshi convincing research?
Das-Munshi et al in 2007 reviewed MCS and Head & Neck Surgery.
Amongst hundreds of research titles, I have never seen another review of MCS and Head & Neck Surgery.

Comment on 4: DIAGNOSIS, TREATMENT & MANAGEMENT OF M.C.S.

Section 4 and the list of references in the working draft could be much improved. I include a condensed list of references of the many hundreds published on MCS[1]. Most of the studies have self-explanatory titles, a number are already included in the working draft, and while this list is not alphabetical, they are in sections.

Testing for MCS (showing objectively measurable defects) has been done with PET brain scans[2,3] and SPECT brain scans[4,5,6]. Oxidative stress can be tested[7] and low natural killer cell function[8,9] (This TILT theory is already listed).

Those less able to metabolise chemicals are at greater risk[10,11]. The Brigham... Hospital case led to a decrease in initiation of new chemical sensitivity when indoor air flow increased[12]

Initiation of chemical sensitivity is documented[13-35] and there are analogies to other conditions[36] MCS and asthma and migraine.

4.1.1 Re the South Australian Surveys (2002 & 2004). Which S.A. doctor would specialise in helping people sensitive to chemicals? The South Australians I've spoken to don't know of a helpful doctor.
So is this why 'only 0.9% reported a medical diagnosis of MCS' ?

4.3 Dr Rea outlines his treatment facility (www.AEHF.com) and possibly Dr Lieberman (www.COEM.com).
Re SA parliamentary inquiry.
paragraph 2: Treatment in public hospitals is on pages 77-79.
What page is paragraph 3 referring to? Minimising chemical exposure is not mentioned, yet repeatedly the inquiry was told of Scent-Free policies in hospitals (p79) and workplaces (p80).
'According to the SATFMCS many commercial fragrances contain industrial solvents and petrochemicals' p79.

4.4 TREATMENT OF MCS Insert after the first paragraph
'A simple test of blood or body fluid has not been developed. A non-invasive test is needed. No testing procedures should leave the patient in worse health'.
Paragraph 6: Include the words 'information and research on toxic chemicals' that the support groups provide or information 'about chemicals, research'
Paragraph 6: List 'total or partial avoidance of chemicals that cause symptoms' first and not last, particularly as over 94% of those surveyed by Gibson et al (of 917 people with MCS) found this treatment to be most helpful.

4.5.1 Longitudinal Study

Specialist doctors could be paid to complete a yearly survey of patients sensitive to chemicals, although not expecting more than a half hour to an hour of their time each year.
A chart indicating patients 1 to 20, with maybe 60 to 80 'treatment' options, including moving to live amongst cleaner outdoor air, or eating organic food, with provision for different levels of [illegible] or none or no change, could monitor many patients.

4.5.2 Education/Training

resulting in 'practical ways to assist people who are affected by MCS'.
Build on the work of Pall, and Rea who operates an environmental centre.
As I wrote on page 2, these three elements can be supported in Australia:

1/ Reduction of overload of pollutants
2/ Biochemistry tests
3/ Nutrient supplements (low allergy, in optional high doses).

The funding for regular tests and supplements should be supported by the Australian government.

5.4.1 Common MCS treatments.
List 'avoidance' of chemicals first, not last.
In addition, biochemistry and nutritional supplements are used by Pall & Rea.

5.4.3 Principles for the management of MCS
This needs reworking, especially after studying Rea's 'Chemical Sensitivity'.
I expect many patients would be told to reduce exposures to poisons and known chemical triggers to begin with.

5.5 SUGGESTIONS FOR CLINICAL RESEARCH.
Most helpful would be specialist doctors, although not expecting more than a half hour of their time each year.

6.5.2 I admire the British (BSAENM) statements re MCS
however instead of hormone mimicry, I prefer the term 'hormone disruption' which these studies of head and neck cancer (Yoo) and breast cancer (Bradlow) illustrate. 40,41
Invoking the precautionary principle is to be recommended.

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You can use any of the information below when writing your own submission. Or you can send this submission, with or without your comments in the space provided overleaf. Include your name and address and email to MCS@nicnas.gov.au or mail to MCS Report, NICNAS, GPO Box 58, Sydney NSW 2001 by 30 January 2009

Submission to:

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

CHEMICAL EXPOSURES

The Working Draft says,

Overall, available data are currently inadequate to identify individuals who are at risk of developing MCS on the basis of the type or extent of their chemical exposures. (p. 17)

Ashford and Miller (1998:235) wrote, "there is accumulating evidence that exposures to organophosphate pesticides, volatile organic chemicals in sick buildings, and various solvents may initiate MCS, based upon observations by independent scientists looking at different groups of individuals. Near-simultaneous onset of MCS in a group of individuals following an identifiable exposure event strongly suggests causation." They listed over a dozen studies – there have been more in the ten years since they wrote the second edition of their book. Exposure to organochlorine pesticides has also been linked to MCS (eg Rea et al. 2001).

There is adequate data to identify individuals at risk of developing MCS on the basis of their chemical exposures. What is unknown is how high the risk is. Some individuals are likely to be at higher risk for genetic or other reasons.

"IDIOPATHIC ENVIRONMENTAL INTOLERANCES"

The Working Draft says,

the descriptor Idiopathic Environmental Intolerance or IEI is favoured by many, including the World Health Organization (WHO), because it does not make inferences with regards to causative agents. (p. 9)

A World Health Organisation workshop on MCS held in 1996 described the condition as an acquired disorder with multiple recurrent symptoms, associated with diverse environmental factors that are tolerated by the majority of people and that is not explained by any known medical or psychiatric/psychological disorder. The workshop also concluded that use of the term MCS should be discontinued because it makes an unsupported judgement on causation noting the existence of several definitions of what has been caused MCS. The workshop favoured the descriptor "Idiopathic Environmental Intolerances" (IPCS, 1996). (p. 13-14)

Invited participants represented a range of disciplines involved in researching, investigating, and treating MCS and other environmental illnesses. (p. 57)

However, Ashford and Miller (1998:279-284) say of this workshop, 'The four "NGO representatives" were full-time employees of BASF, Bayer, Monsanto, and Coca Cola, the first three of which claimed affiliation with an industry-funded science institute (the European Centre for Environment and Toxicology).' Ronald Gots, director of the Environmental Sensitivities Research Institute, whose members included DowElanco, Monsanto, Procter and Gamble, and the Cosmetic Toiletries and Fragrances Association, was a participant and 'was also invited to give the "U.S. perspective" on MCS'. Various outside "observers", some of whom were involved in a lawsuit about "wood preservative syndrome", were involved in drafting and possibly voting on the recommendations. After certain participants wrongly claimed that IEI was now WHO's official name for MCS and IPCS received a letter of protest from 80 prominent U.S. scientists and physicians, 'IPCS clarified the status of the IEI name by issuing a notice stating that WHO had "neither adopted nor endorsed a policy or scientific opinion on MCS."' The report now contains disclaimers, including 'that the document does not necessarily represent the decisions or stated policy of UNEP, ILO, or WHO, that it does not constitute a formal publication; and that it should not be reviewed, abstracted or quoted without the written permission of the Director of the IPCS.'

The Working Draft's comments on this workshop are misleading and inappropriate. The statement that WHO favours the term "Idiopathic Environmental Intolerances" is incorrect.

It is also wrong to say that "*Idiopathic Environmental Intolerance or IEI ... does not make inferences with regards to causative agents*". Idiopathic means "of unknown cause" so it denies the possibility that MCS can be initiated by chemical exposure.

SMELLS

The Working Draft says,

Some challenge tests suggest that it is the smell or odour of a triggering agent, rather any of its pharmacological or toxicological properties per se that elicit MCS symptoms. (pp. 6, 8, 39)

The Working Draft doesn't say which challenge tests are referred to here, but there have been serious flaws in a number of them (Ashford and Miller 1998:218-223, Goudsmit 2008). People with MCS react to chemicals, not to the smell of chemicals. There are people with MCS who have no sense of smell and many others who have reacted to chemicals they couldn't smell. There are studies showing that smell is not involved, such as Millqvist et al. (1999)

PSYCHOGENIC COMPONENT

The Working Draft says,

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. (p. 31)

The working draft is not thorough enough to come to an honest conclusion about the scientific weight of evidence for the cause of MCS. The far more comprehensive and

rigorous book by Ashford and Miller (1998) concluded that there was far more evidence for physiological mechanisms than for psychological ones. Since then the gap has widened, particularly with genetic studies pointing clearly to physiological mechanisms.

Bear in mind that in the past the following diseases have been falsely claimed to be psychological: multiple sclerosis, Parkinson's disease, lupus, migraine, rheumatoid arthritis, asthma, ulcerative colitis and gastric ulcers (Pall 2007:202-206).

DIAGNOSIS AND TREATMENT

The Working Draft says,

The diagnosis of MCS is currently based on self-reported symptoms. (p.6)

It also says,

For diagnosis, Ashford and Miller (1991) additionally proposed that a patient could be shown to have MCS under carefully controlled double-blinded conditions when, upon removal of the offending agents, their symptoms cleared and returned when rechallenged by the specific agents. (p. 13)

In Victoria some patients with MCS were tested in the way Ashford and Miller proposed.

Working Draft says,

In the past, there have been specific private facilities in Australia catering for the chemically sensitive.

Importantly, the South Australian Parliamentary Inquiry heard that patients with MCS attributed the majority of the benefits they experienced to education, support and acknowledgement of the illness (Social Development Committee Report, 2005). (p. 37)

The comment made to the South Australian Parliamentary Inquiry only referred to the Sydney clinic, not to the Melbourne Environmental Control Units. Many people who were patients in the Melbourne ECUs have benefited enormously from finding out exactly which chemicals and foods affected them and how.

The Working Draft says,

"a clinical consultancy has been undertaken to identify current diagnosis and treatment practices" (p. 2)

In this case current diagnosis and treatment practices should be listed.

The Working Draft says,

Responses to questionnaires demonstrated that individual clinical views were polarised, vigorously stated and defended, based mainly on individual belief and limited clinical experience. (p. 45)

It is not clear why clinicians with "limited clinical experience" participated. It would have been more useful to look at methods used to treat MCS overseas. For example, *Chemical Sensitivity Volume 4: Tools of Diagnosis and Methods of Treatment* (Rea 1997) draws on studies of more than 20,000 patients at the Environmental Health Center in Dallas.

The Working Draft says,

MCS Clinical Management Principles

- *Accept that the person with MCS feels ill and is disabled by the illness;*
- *Provide an empathic relationship to offer understanding and support;*
- *Encourage self-management rather than offering or seeking a cure;*
- *Recognise and explain that no specific therapy has yet been proven to be of benefit;*
- *Maintain a long-term positive approach. (p. 39)*

This is totally inadequate, particularly for people with MCS who have severe symptoms, food sensitivities or special difficulties, such as children affected by chemicals at school or elderly people needing access to aged care. As chemicals in most medical clinics (including fragrances) make people with MCS sick, these principles are not even practical.

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Email MCS@nicnas.gov.au or mail to MCS Report, NICNAS, GPO Box 58, Sydney NSW 2001 by 30 January 2009.

N.B. Submissions will become public documents published on the NICNAS or OCS website. If you would like your submission to remain confidential contact NICNAS/OCS. (OCS freecall 1800 170 723, NICNAS 1800 638 528)

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