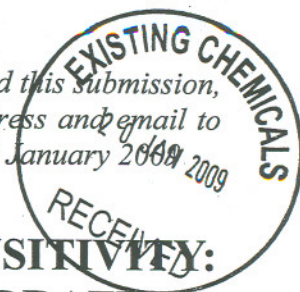


You can use any of the information below when writing your own submission. Or you can send this submission, with or without your comments in the space provided overleaf. Include your name and address and email to MCS@nicnas.gov.au or mail to MCS Report, NICNAS, GPO Box 58, Sydney NSW 2001 by 30 January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

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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 re-challenged by the specific agents. (p. 13)

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

The 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

You may like to add your own comments here and/or attach another piece of paper:

..... People suffering from MCS..... DO NOT simply react
..... to "smells"..... We do not always "smell" the
..... thing that is causing reactions..... Luckily we can
..... "SMELL" the fragrance products on other people and are
..... therefore warned to leave the area before reactions
..... become acute..... NOT SO with some other chemicals.....

Your name EILEEN SILVESTR

Address

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)

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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