

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

INTRODUCTION.

This draft report is controversial, with a strong psychogenic bias, and is poorly drafted. It is therefore unlikely to address the multitude of serious problems faced by all persons in Australian society with ES/MCS who have been poisoned by toxic substances in the environment – especially infants, children, the disabled, and the frail aged and those with MCS who also have other serious/chronic health conditions.

As long as government fails to address the issues surrounding exposure to the multitude of chemicals we encounter on a daily basis, the issue of MCS and other environmental sensitivities cannot be satisfactorily addressed e.g.:

- concentrations of chemicals in all of our environments – domestic, workplace, wider environment
- the lack of toxicology for most of these, both singly and as mixtures,
- the recognition of poisonings at government and medical level,
- treatment and management,
- co-existing morbidities between MCS and other diseases e.g. airway disease
- education of the public re MCS and chemical usage. Often people are shocked to find that the chemicals they are using are not as safe as they thought - especially once their health has been damaged and they cannot get help. This demonstrates the need for government action to encourage people to reduce chemicals in their lives.
- The opportunity to develop green chemicals that are non toxic and sustainable

We are especially concerned about the impacts of gene technology and nanotechnology on human health and the environment as we haven't caught up with existing technology yet.

Some criticisms of the document are as follows:

- It is clear there is a genetic component to MCS and there is little evidence that OCS/NICNAS reviewed scientific and medical literature on recent research into genetic mechanisms.
- It cannot be claimed that MCS is not an organic disease until all avenues of investigation have been explored.
- The socio-economic impact of MCS and other environmental sensitivities have not been investigated.
- The health impact of environmental pollution on humans has not been adequately investigated. While it is clear there is an environmental impact from chemical pollution and wildlife is under threat, humans are a threatened species as well.

A primary 'psychological/psychiatric' pathogenesis cannot be justified. This view has changed in recent years. Studies that previously supported a psychological aetiology have been discredited. The pre-release report has included a further 13 references published after 2006 when the BMP consulting group report was completed. Of these eight were clearly added to lend weight to the psychological/psychiatric basis of MCS. This data can work as a dismissal of MCS rather than an attempt to understand and implement measures that would ease the pain and suffering of those with MCS. The persistence in demonstrating a psychological/psychiatric basis does not appear to be by the Australian Psychological Society, as on p41 of the report states that "The APS was unable to find a member with a specialisation or interest in MCS for interview or completion of the questionnaire, and was also unable to provide any information on the possible role of their membership with individuals with MCS." MCS is a serious and disabling illness with no single diagnostic test and it is clear that a range of factors contribute to its pathogenesis.

As was the position with the CFS Guidelines in 2002, research into the aetiology, pathology and treatment of MCS is necessary. We need to learn from the CFS Guidelines controversy and the MCS review should not go down that path especially as there are many overlaps and it looks to be the same condition. If the review finds for a primary psychogenic diagnosis and after some research MCS/CFS/FM are found to be the same condition or the pathophysiology of MCS is found, the government will look ridiculous on the World stage.

It is reprehensible that Medicine cannot acknowledge things it does not understand. Although the pathogenesis of MCS is not fully understood, this does not make it right to decide MCS is a psychological problem (Read. 2002 p. 25, para. 4). Such an approach cannot be justified either medically or ethically. The reference to an MCS belief system is discriminatory. The belief system of the medical profession and government must change if we are going to be able to move forward.

Patients with allergy/sensitivity reactions to even "low levels" of chemicals in medications are not deemed "psychogenic" but worthy of appropriate support and care; and given medical sanction to avoid the medication/substance trigger to prevent another adverse outcome. Whereas patients who have significant potentially life threatening reactions to chemical triggers/incitants are labeled as psychogenic and not provided with safe access and appropriate care in health care facilities.

It is shocking that this draft report still questions the physiological validity of MCS instead preferring an outdated strong psychogenic bias. A psychological overlay can occur in any individuals with any chronic debilitating condition when they are unable to get medical, social and welfare assistance, whether they have MCS or not. Those with MCS may become isolated with situational depression because of poor quality of life given the restrictions their condition places on their life, health, work, and social/family relationships. Many become traumatized and suicidal and for these individuals supportive crisis/psychological counselling or psychiatric interventions as a part of the overall medical care of MCS may be indicated. The feeling of being isolated, desperate and helpless happens with many diseases and should always be seen in context as with other conditions.

Those with other unrelated severe/ chronic conditions do not commonly encounter a climate of disbelief and denial. Instead supportive counselling is frequently offered without a psychogenic primary label to building coping strategies to assist with enabling adaption to their condition, with provision of safe access to supportive healthcare/services. Whereas people with ES/MCS who seek assistance commonly experience a climate of illness disbelief and denial by government/service providers; a lack of safe access to healthcare, services, facilities, compounded with a general lack of support which can understandably lead to suicide in some cases.

Lack of education about the dangers of chemicals and MCS can also add to the distress of individuals with MCS. In addition their self-management efforts can be misunderstood by the general public and police, who may then involve local mental health services. Some individuals with MCS have been wrongfully detained in a mental health facility which is basically dangerous for them (Sears, M E 2007). Once detained they are in an unsafe environment in which they can be exposed to triggering substances that can cause more harm, and if medicated can suffer dangerous reactions – individuals with MCS can die as a result of chemical exposure. We need the best outcome from this review to ensure that this NEVER happens again.

The model for MCS should be an integrated model that encompasses a medical, social and disability approach. We also think that the model for MCS should not be looking at various body systems but should take a whole of body approach.

Some research needs to be carried out to ascertain how many people in the community have MCS and the socio-economic cost of these. The government needs to look at:

- lost tax revenue,
- lost productivity,
- health and welfare costs.

In its current form the OCS/NICNAS report will:

- contribute nothing to the MCS debate,
- clinicians will not lose their bias,
- the debate will remain polarised
- individuals with MCS, especially the very severe sufferers, will remain extremely disadvantaged as they will continue to be considered as psychiatric cases;
- they will not be taken seriously;
- not be included in health and disability policy,
- not included in service planning and delivery;
- their issues of safe access to essential services will continue to be ignored;
- some may even be erroneously detained by psychiatric services, further harmed or traumatized,
- their human rights will continue to be ignored and
- their fundamental needs will not be met – all of which is unacceptable.

Individuals with MCS need to be protected by legislation to ensure that they are treated with dignity and respect, can access necessary services in a safe and timely manner and are not erroneously detained by psychiatric services, local police or under notice by national security organisations when they need to wear a mask as a medical aid to prevent a significant/life threatening adverse reaction to various chemical/incitant triggers in the environment.

## RESPONSES TO MCS REVIEW DRAFT REPORT

### ENVIRONMENTAL SENSITIVITIES/MCS

The government funded Environmental Health/Research Centre in Canada “acknowledges the critical health problems and growing concern throughout Canada and the rest of the world associated with the environment. Some people who experience intensive, or ongoing or cumulative, low level exposures to one or more chemicals or irritants become sensitized to them. People with environmental sensitivities often become ill ....marked by debilitating symptoms affecting multi organ symptoms. Frequency and or severity of these symptoms are made worse by subsequent exposures even at very low doses to a wide range of chemicals and irritants.”

### OVERLAP WITH OTHER DISORDERS

The Canadian Consensus Document Report 2003 on CFS/ME authored by Professors/Specialists in Medicine, Psychiatry, Psychology, Pathology, Immunology fields reached a consensus that patients may have new sensitivities to food, medications and/or chemicals; and “co-morbid entities such as MCS et al may occur in the setting of ME/CFS and should be considered as overlap syndromes.

There are many existing co-morbidities between MCS and other diseases so the symptoms of many diseases can be expected to overlap. (MCS Referral and Resources) (see appendix). MCS/hypersensitivity to chemicals has been associated with allergy and other disorders such CFS & Fibromyalgia (Meggs et al, 1996; Caress and Steineman, 2005; Lacour et al, 2005). It has been suggested that allergy may be a risk factor in chemically sensitivity patients for the development of respiratory disorders such as RADS and food allergy/sensitivity (RIDS) Meggs et al, 1996; Caress and Steineman, 2005.

### CHEMICAL EXPOSURES

The Working Draft states: “Overall, available data is 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)”

COMMENTS: 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. Ashford and Miller (1998:235) state "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/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 theirbook. Exposure to organochlorine pesticides has also been linked to MCS (eg Rea et al. 2001).

The Australian Worksafe Standard validates sensitisation and low level exposures

Chapter 12 Sensitisers p. 17

- ◆ 12.1 Some substances (TDI, Formaldehyde) can cause a specific immune response in some people. This is known as 'sensitisation';
- ◆ 12.2 Following sensitisation 'an affected individual may subsequently react to exposure to minute levels of that substance'. Although low values have been assigned the exposure standard may not be adequate to protect a hypersensitive individual and persons who are sensitised to a particular substance should not further be exposed to that substance.

Chapter 15 Mixtures of substances p. 28

- ◆ 15.12 At present the understanding of interaction effects is incomplete. The knowledge that such effects occur is reason to maintain the concentrations of individual substances as low as is practicable under complex exposure conditions (Worksafe Standard. 2005).

Some points of interest in the Australian Worksafe Standard are as follows:

Introduction p. 5

- ◆ 1.2 exposure standards are based only on current knowledge;
- ◆ 1.4 exposure standards do not guarantee protection for every worker because of individual susceptibility and biological variation, and it is inevitable that some workers will suffer adverse health impacts;
- ◆ 1.6 atmospheric exposure standards only consider absorption by inhalation and are only valid on the assumption that skin absorption cannot occur.

Most substances used are untested/lack data

Chapter 2. Unlisted substances p. 6

- ◆ 2.1 most substances used in industry have not been assigned exposure standards. This does not imply that the substances are safe or non-hazardous;
- ◆ 2.2 there is a lack of data on health effects of some substances to assign a standard.

Lack of biological tests

Chapter 8. Biological monitoring p. 13

- ◆ 8.3 there is limited knowledge of suitable and definitive biological tests for most substances (Worksafe Standard. 2005)

Part 2 Interpretation p. 70

'Exposure Standard' means an airborne concentration of a particular substance in the workers breathing zone, especially to which according to current knowledge, should no cause adverse health effects nor cause undue discomfort to nearly all workers . (Worksafe Standard. 1995).

## SMELL/ODOURS

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

COMMENTS: The Working Draft does not 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)

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Odour and chemical interactions validated. Some points of interest in the Australian Worksafe Standard are as follows: Chapter 9 Odour thresholds p.14 9.1 odours can serve as a useful warning signal as to the presence of a substance in the environment;9.2 there may be interference from other substances;Avoidance validated

Chapter 11 Effects on the skin p. 16

- ◆ 11.1 some substances can readily penetrate the skin and this method of exposure can pose a far greater danger than inhalation exposure;
- ◆ 11.3 some substances such as solvents can accelerate or alter the rate of skin absorption;
- ◆ 11.6 it is 'good practice' to avoid any unnecessary contact with all chemical substances (Worksafe Standard. 2005)

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In a two year period more than 500 employees from a Nova Scotia hospital were examined due to indoor air quality and in the course of seven months many had developed chemical hypersensitivity including MCS. The majority identified odours as the most common triggering factor. This led to hospital management and the labour union issuing a ban on fragrances and fragrance containing products in the hospital. Many other sectors in the area have since taken similar initiatives (Silberschmidt, M. 2005 p. 77).

#### IDIOPATHIC ENVIRONMENTAL INTOLERANCES'

The Working Draft claims:" 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)"

COMMENTS: Idiopathic means "of unknown cause" so it denies the possibility that MCS can be initiated by chemical exposure. It is therefore wrong to claim that "Idiopathic environmental Intolerance or IEI...does not make inferences with regards to causative agents".

The Working Draft also states: 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, psychiatric, or 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 caused MCS. The workshop favoured the descriptor " Idiopathic Environmental Intolerances " (IPCS, I 996 (p 13-14). Invited participants represented a range of disciplines involved in researching, investigating, and treating MCS and other environmental illnesses." (p. 57)

COMMENTS: The above draft statement is false and misleading. 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 Dow Elanco, Monsanto, Procter and Gamble, and the Cosmetic Toiletries and Fragrances Association, was a participant and 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 the 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 the " 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 the WHO favours the term "Idiopathic Environmental Intolerances" is incorrect.

Pamela Reed Gibson Psychology Professor of James Madison University has found that " the proposed name for the condition (IEI,MCS et al) often reflects the bias of the user (medical/psychogenic approach)".1993(p6)

#### PSYCHOGENIC COMPONENT

However the working Draft claims: "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 it's pathogenesis". (p.31).

COMMENTS: Overall there is a strong bias and heavy psychogenic emphasis throughout the draft, which is not thorough enough to come to an honest conclusion about the scientific weight of evidence for the cause of MCS. The far more rigorous book by Ashford and Miller (1998) concluded there was far more evidence for physiological mechanisms than for psychological mechanisms. Since then the gap has widened, particularly with genetic studies pointing clearly to physiological mechanisms. Bear in mind that 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).

A recent review of medical evidence commissioned by the Canadian Human Rights Commission concludes “the balance of scientific evidence and experience indicates E/S generally arise from physiological causes, although there are many neurological and psychological consequences. Sears 2007.p26.”

Pamela Reed Gibson Professor of Psychology at the James Madison University found:

- People with ES/MCS suffer severe stress and trauma, isolation and inherent loss issues.
- Are without much needed support for a difficult chronic health condition.
- Experience severe life disruption with little medical, legal and economic aid and area hidden population
- Often face financial destitution, homelessness, isolation, and ostracism from their culture and family.
- Neurological or psychiatric effects may be direct toxicological reactions to incitants or long term consequences of living with a disabling illness for which there is almost no help, accommodation, or benefits exist. (Gibson 2007:p,7).

#### HUMAN RIGHTS ISSUES

The government funded Nova Scotia Environmental Health Centre in Canada has a strict No Scents Policy for the safety of patients and public. However, in Australia people with severe ES/MCS are unable to safely access services such as hospitals, medical centres, allied health facilities, schools, aged care facilities, respite care, home care, home nursing, meals on wheels, and HACC funded services due to lack of a No Scent/Perfume Policy.

It is a serious indictment against our government when very frail aged persons with MCS and serious cardiovascular, respiratory, terminal conditions such as emphysema, are unable to safely access care and accommodation with hospitals, HACC, and aged care services/facilities; because they are at risk of a dangerous life threatening anaphylactic reaction due to failure to implement a No Scents/Perfume Policy.

In Victoria a woman experienced a serious life threatening anaphylactic reaction to perfume worn by health care staff in a Hospital. The case was referred to the Human Rights Commissioner in Victoria who concluded “all Victorians should be able to get healthcare in a public hospital without running the risk of death or serious health problems. A Fragrance-free Policy is a very good idea. I will be pursuing this with healthcare providers” (The Age 30<sup>th</sup> November, 2008)

#### LEGAL ISSUES

The draft report emphasis on questioning the right of MCS persons to legitimately seek legal or financial assistance/compensation infers a malingerer stereotype. It is discriminatory and denies fundamental Human Rights and equal opportunity access to assistance. Whereas legal and financial, social security payments, superannuation/workers/scompensation and disability payments, are deemed legitimate for persons with other types of significant chronic illness/disabilities. MCS disability legitimately exists in law and our government needs to acknowledge this by ensuring safe access through federal legislation, policies/guidelines.

While MCS is considered a controversial diagnosis by the medical profession, it is recognized as a disability. The Australian Human Rights Commission accepts MCS as a disability (Personal correspondence) and recently amended their building access guidelines to allow access to those who are sensitive to chemicals.

The Canadian Human Rights Commission on June 15, 2007 approved their Policy on Environmental Sensitivities. They state that environmental sensitivities is a medical condition and a disability entitled to the protection of the Canadian Human Rights Act which prohibits discrimination on the basis of disability.

#### LEGAL PERSPECTIVE ON ENVIRONMENTAL SENSITIVITIES

The Legal Perspective Report on Accommodation for Environmental Sensitivities for the Canadian Human Rights Commission states: "Definition of Disability: the inability of the medical profession to diagnose a condition or identify its cause does not affect whether an individual has a disability so long as it's triggers can be identified". ..., "environmental sensitivities are often misdiagnosed as psychological or psychiatric conditions. This misdiagnosis and misunderstanding results in social stigma for people with sensitivities and may result in denial of accommodation with individuals being told "it is in your head".....There is no doubt that individuals experience physical symptoms as a result of environmental agents". Wilkie & Baker p.8,2007).

NICNAS/OCS commissioned an independent medical review report on MCS, which should be on the public record in accordance with principles of transparency and accountability, as is the case for two commissioned reports on ES/MCS for the Canadian Human Rights Commission.

#### DIAGNOSIS AND TREATMENT

The Working Draft states "the diagnosis of MCS is currently based on self-reported symptoms". (p6).

Whereas, the Working Draft also stated "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).

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

Furthermore, diagnosis of Environmental Sensitivities/MCS at the Nova Scotia Environmental Centre in Canada includes a thorough physical examination, "taking an environmental history ....and the Doctor may order blood tests to evaluate levels of chemical contaminants or their metabolites, antibodies to specific chemicals, depollution enzymes et al. "

The Working Draft states: "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).

COMMENTS: 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 ECU's have benefited enormously from finding out exactly how and which chemicals and foods affected them. Also in a psychological study of

917 persons with MCS 95% reported chemical free living space, avoidance , and prayer were helpful.( Pamela Reed Gibson & Lindberg A 2007 p.22 (7), 717-732) Avoidance of triggers as helpful is a consistent finding.

The Working Draft states: A clinical consultancy has been undertaken to identify current diagnosis and treatment practices” . Current diagnosis and treatment practices should have been clearly stated by the Working Draft.

The Working Draft states: “Responses to questionnaires demonstrated individual clinical views were polarized, 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 e.g studies of more than 20,000 patients at the Environmental Health Center in Dallas.

It is noteworthy that members of the medical profession including Psychiatrists suffering chemical sensitivities have sought consultation and Specialist treatment in Dallas. (Rea 1997: Chemical Sensitivity Volume 4:Tools of Diagnosis and Methods of Treatment).

The Working Draft states: Medical Practitioner Principles: Accept 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; Recognize and explain that no specific therapy has yet been proven to be of benefit; maintain a long-term positive approach. (p.39)

COMMENTS: These principles are totally inadequate. They do not encourage General Medical Practitioners to monitor, evaluate, assess general health needs of those with MCS.

Individuals with MCS may require the following assistance: “advocacy, assistance with chronic illness, Information, ancillary services,home care, home nursing, meals on wheels, HACC services, meeting special needs including respite care, collaborative health care , GP, Specialist care/chronic illness management courses, disability support/design and product centres, Loss/grief/general counseling, Physicians, “alternative” health practitioners with symptomatic treatments, legal and financial assistance, medico-legal issues, financial support, social security, superannuation/workers/disability payout/compensation, childcare, debt-help organizations transport/parking concerns.” AMA G.Practitioner CFS Guidelines.(p16).

## 2.5 CAN A CLINICAL DIAGNOSIS FOR MCS BE MADE

COMMENTS: A clinical diagnosis is acceptable for some diseases – why not MCS!

The definition of MCS is sufficiently documented by Cullen and is still in use with some modifications by most environmental specialists. We should not be wasting time with this unless a better definition has been documented. . Hopefully this will come from Canada who have medical facilities dedicated to environmental sensitivities and can gather the evidence based data required to resolve many of the current problems and biases.

Supporting Information:

MCS is accepted as a physical disease in Denmark, Canada, New Zealand, and by the Institute of occupational Medicine, Edinburgh (Silberschmidt, M. 2005; Sears, M E. 2007; Read, D. 2002; Gravelling, R A et al. 1999). Why is Australia different?

'Most international experts within the field agree that on the basis of epidemiological data, MCS is a reality' (Silberschmidt, M. 2005 p.90).

Levin and Byers in the AOEC workshop on MCS in 1991 claim that MCS is easy to diagnose and treat. They list diagnostic tests in their presentation as do Ashford and Miller in their book (Levin A S & Byers V S. 1992; Ashford N A and Miller, C J. 1998 Appendix B p. 359)

Rea and Miller ensure that when testing is done, offending agents are removed and symptoms cleared prior to challenges. Rea and Miller test in environmental control units to ensure the tests are not compromised. (Rea, W J. 1998; Ashford, N and Miller, C. 1998)

Double blind placebo controlled challenge testing. In some studies substances used as placebos are not inert and may trigger reactions. Care needs to be taken that in studies where placebos are used that these are truly inert substances that cannot trigger reactions. Individuals may need to be allergy tested with respect to planned placebos.

A criticism made by references in the MCS review of double blind studies, is that some do not use an 'olfactory masking agent', but the masking agent itself may cause a reaction and therefore bias a studies conclusion toward psychological when subjects are unable to distinguish. So many different and conflicting reports means that NO conclusion should be drawn until some consistency and appropriate testing protocols are established. The study by Staudenmayer et al, 1993 should be discounted for this reason.

Another problem with this type of invasive challenge testing is that the individual is likely to have adverse reactions to the chemicals during the challenge. This is not for the benefit of the individual.

#### Other types of testing

Dermatologists have used patch testing for decades. They use a mix of terpenes to test for fragrance allergy. ([www.dermnet.org.nz](http://www.dermnet.org.nz)). For some chemicals the term chemical allergy is appropriate (Amdur, M O et al. 1991 Chapter 2; Bernstein, D I. 1996). Allergists use skin tests i.e. scratch or prick tests to test for allergy. Some Environmental Medicine practitioners use intradermal testing to test for chemical reactivity. Methods used by practitioners of environmental medicine need to be investigated without bias.

Genova Diagnostics [www.GDX.net](http://www.GDX.net) have a range of diagnostic tests to assist in the diagnosis and management of MCS. The tests include Detoxification Profile, Oxidative stress markers and Genetic Predisposition analysis.

It is only though further targeted research into the causes of chemical sensitivity that a range of tests for MCS will be available. Given the ubiquitous nature of chemicals in our environment we doubt that it is possible now when studies are planned to find controls.

Individuals with MCS usually have other diseases, some of which are chronic, painful and disabling conditions not necessarily related to MCS, and can be diseases requiring health interventions. Such conditions can be missed or left untreated if an individual is thought to have a primary psychological problem and individuals with MCS will simply go on suffering the most appalling physical distress, compounded by insults and inhumanity.

Those of us who know we have MCS now are just the thin edge of the wedge, many, many, more will follow. The cost of allowing the debate to remain polarised and not do anything about MCS and its causes will be much more expensive in years to come than currently is the case.

Currently, we are subject to human rights abuses that we do not expect in a developed country. The current Working Draft Report will perpetuate Human rights abuses and discrimination. Positive feedback and progress from OCS/NICNAS is needed so that we can have safe access to schools, appropriate healthcare, aged care services and accommodation.

The federal Department of Health and Aging advocates prevention, early intervention, best practice handling of chronic disease; quality of aged care service provision to reduce gaps, and improving accountability, transparency, and accessibility.

The NICNAS/OCS mission statement states “regulation of industrial chemicals for the protection of human health and the environment to deliver safe use of chemicals”. We have to wonder why the National Chemical Regulator, Office of Chemical Safety, abrogates its duty of care to those in the community with MCS. To continue on this path is to have callous disregard for human suffering.

There is a way forward. Government should legislate, develop policies and guidelines to protect persons with MCS, and urgently implement Fragrance Free Policies in hospitals, Allied Health and Aged/Chronic Care facilities and schools.

The federal and state governments together with Education and Service Providers, Employers, Healthcare and Aged Care Industries should pro-actively take steps to minimize chemical use; purchase less toxic products, and advocate with manufacturers/industries to produce less toxic products and chemicals to protect all human health in Australia now and for the future.



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