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A Personal submission to NICNAS in response to “A Review of Multiple Chemical Sensitivity – Working Draft Report” released in November 2008.

My comments are based on my own personal experience living with MCS, helping those with the condition, and research I have read.

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Page 7 Notes: 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.

My response: Whilst people with MCS describe the smell of a substance, it is not the smell that elicits the reaction it is the chemical substance of an object. This is also true of naturally forming chemicals within natural substances, such as plant life and foods. Odours can be perceived differently for different sufferers and to describe a chemical as a smell is misleading, and will never identify the chemical that maybe causing the reaction. This would hinder future research. People with MCS should be taken more seriously; they are often referred to as canaries in the coalmine, and can usually identify toxic levels of a substance or environment well before science discovers it to be.

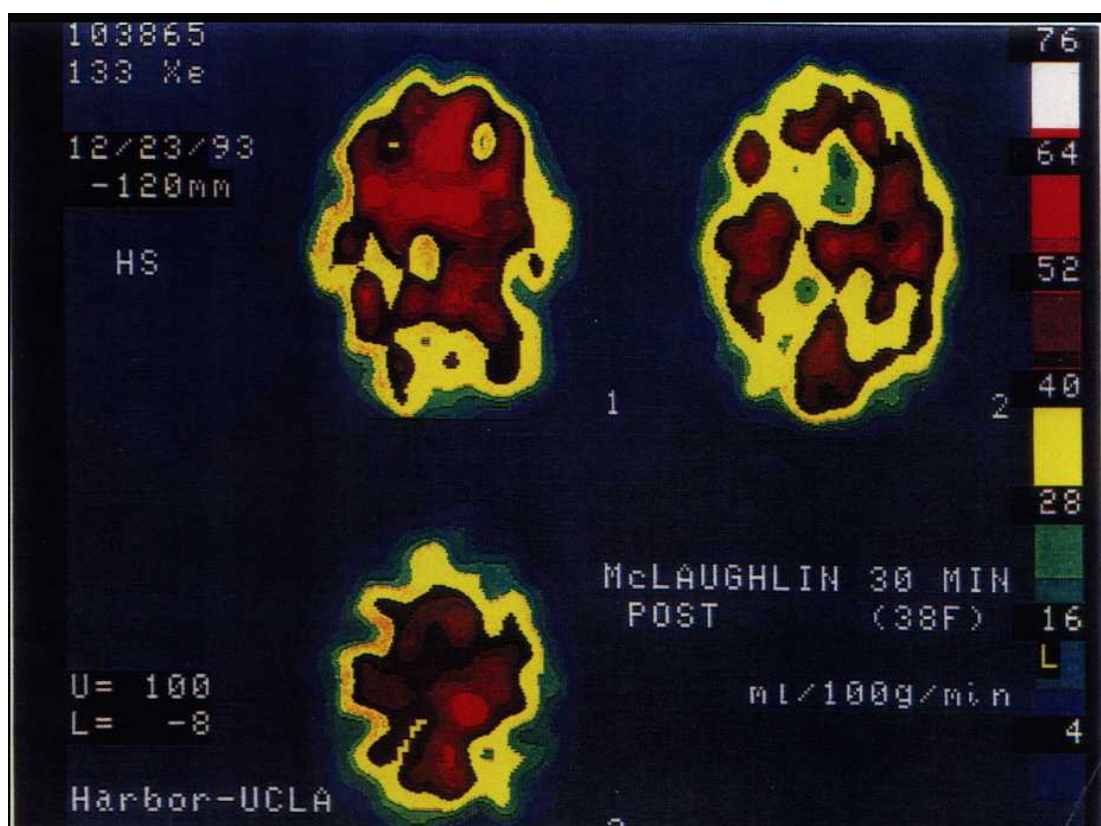
Research also shows that many people with MCS have a heightened sense of smell; however there are also sufferers of MCS who have little or NO sense of smell, yet still elicit a reaction. (1) Therefore, how can a smell be a triggering agent, in those with MCS who have No sense of smell?

Page 7 Notes: No laboratory tests currently exist for diagnosing MCS.

My response: There are other illnesses that do not have laboratory tests for diagnosis. Examples are: Chronic Fatigue Syndrome, SIDS and Mental illnesses such as bi-bolar. Patients with MCS usually go through a number of laboratory tests to eliminate all other possibilities, for example lupus, RNA levels, and other general blood work as a means of elimination.

People with MCS can be tested via inhalation & injection as a marker of their sensitivity.(2) Environmental care units uses challenge tests, as used by Dr Rae in Texas and Dr Rapp in Buffalo. Doris Rapp has a website and in particular is a book called “Is this your child’s World” that clearly shows the effects of chemicals on children. It documents how the testing procedures work, how their behaviour is affected and their handwriting altered. This is also on video. <http://www.drrapp.com>

SPEC scans are also used and I draw your attention to the effect that perfume has on a person's brain with MCS.



EEG abnormalities have been reported in MCS subjects (Miller, 1992) and in persons exposed to AChE inhibitors, such as OPs (Duffy, Burchfiel, et al., 1979; Duffy and Burchfiel, 1980) EEG abnormalities are seen in patients with known exposure to widely recognized neurotoxins "including petroleum distillates and pesticides" (Simon, Hickey, et al., 1994). Isaac Silberman, M.D., Neurologist, San Francisco, also found patients with MCS have abnormal EEG's in particular when challenged with a substance to which they were particularly sensitive.

Dr Gunnar Heuser specialises in immunotoxicology and neurotoxicity with a particular interest in studies performed on people who have MCS. Dr Heuser has written numerous papers for medical journals on Sperm Morphology and toxic exposure. His study on chemically sensitive patients found 50-70% of MCS patients had declining fertility rates and sperm abnormalities, compared to the control group which showed 5-30%. Since these significant findings, Heuser recommends a sperm test for every male MCS patient. (3) Sophisticated methodology such as used by Dr Heuser is essential for people who are chemically exposed. (4) People with MCS look okay; all parameters that a regular physician uses will not show anything, including a physical examination, blood count & chemistry and thus may totally miss a profound effect from toxic exposure, demonstrated by a sperm test in men.

1.2.1 – Page 7: Research into the cause(s) of MCS Notes: Medical/scientific opinion suggests that MCS has a multifactorial origin, involving physiological, psychological and social predispositions.

My response: Multiple Chemical Sensitivity (MCS) has been the subject of clinical observation and medical debate for almost half a century yet the reference to a chemical injury appears to have been in existence since the 1880's. The concept of environmental illness can be found in medical treatises dating back to the 1880's. ⁽⁵⁾ Beard, (1880, 1881) an American Neurologist described neurasthenia as a functional disease of the nervous system, without structural organic changes, but distinct from mental illness or insanity, resulting largely from environmental factors. ⁽⁶⁾ Neurasthenia emerged in 1800's - as did the introduction of Chemical agriculture. ⁽⁵⁾ Scientists have recently hypothesized that MCS has adopted the organic inheritance of Beard's former concept of neurasthenia. ⁽⁷⁾

Some researchers contend that MCS is psychological, but this hypothesis has failed to prove a psychological link to the illness. ^(8, 9) Evidence to support this is mounting. ⁽¹⁰⁾

- MCS is reproducible in animals. ^(11,12)
- MCS yields clear results with *in vivo* tests such as PET scans, MRI and liver enzyme tests. ^(13, 14,15,16,17,18,19)
- MCS sufferers have temporal lobe impairment, schizophrenics and other psychiatric patients have frontal lobe damage. ⁽²⁰⁾
- Neurological signs including abnormal EEGs and MRIs ^(3,21)
- Pesticides can be found in the blood ⁽¹⁾

The most current research into MCS is by Dr Martin Pall from the School of Molecular Biosciences, Washington State University. The research shows excess elevations of nitric oxide/perioxynitrite cause MCS ⁽²³⁾ of which is mentioned in the report.

Nitric oxide (NO) inhibits cytochrome P-450 activity and slows degradation of hydrophobic organic chemicals. This means that excess nitric oxide slows down the body's natural detoxification processes leaving MCS patients subject to the effects of chemical exposure longer than non-sufferers. Between a reduced blood-brain barrier and increased time to naturally detoxify the body, MCS patients are subject to permanent and long-term brain and nervous system damage which includes toxic encephalopathy. ^(22, 23, 24, 25, 26)

One of the most common terms used by people with MCS is "brain fog". It does affect your neurological functioning, when exposed, but should not be viewed as a psychological illness, as it is a secondary response, as too is the depression from the alienation experienced with the condition.

Page 8 – Longitudinal Study

My response: Studies exist in the support groups around Australia. Data is gathered by the support group when you join. People with MCS 99.9% of the time can identify the onset of their MCS, and is usually recorded on their application forms. For example, in Western Australia, individuals have developed MCS living near /working in a highly industrialised area. Like those near Alcoa, the Atlas Tip Site and the pesticide applicators in the Kimberley's. All these people were able to identify the onset of their illness, being environmental. It is common for people to develop MCS after over exposure to pesticides. Perhaps permission might be sought to obtain those records. I tried several years ago to collate this information, but was unable due to privacy acts. This could easily be gathered in the next census, by those wishing to disclose that information. Programs such as Public Health Mapping and Geographic Information Systems (GIS) may also be useful in gathering MCS statistics. International mapping and monitoring of environments or population health makes managing possible hazards with foresight and will strengthen all MCS health programs locally, nationally and globally.

Education/training – Page 8

The education and training of professionals has largely been placed upon the sufferers themselves. Through a collective of information based on their own life's experiences, self help groups, professionals and individuals have produced information booklets and protocol for hospitals, doctors, friends, family and the general public. There are also tips and advice on exposure reduction within the home and environment to reduce symptoms. This valuable information that need not be reproduced is easily obtained and can be a valuable resource for training. Training is important as there is a critical period in the development of MCS, like many other illnesses.

Early diagnosis is critical, if there is to be any form of minor reversal of the illness. In Australia in 1994, Dr Winder reviewed cases of what he termed at that time "chemically related chronic fatigue syndrome" (Winder, 1994). He considered that early detection and intervention including minimising exposure to the triggers resulted in improved outcomes. Chris Winder an associate professor in Sydney describes the three distinct phases of MCS and the importance of early diagnosis and treatment and states; "The stage of the condition that any person progresses to is invariably a matter of appropriate diligence by MCS sufferers, their medical advisers and sometimes, their employers".

The distinct phases:

- initial signs and symptoms to low level exposure to chemicals which recede with avoidance of exposure;

- reversible sensitivity, with intensifying signs and symptoms after continuing exposure, but partial or total reversal of symptoms after recognition of the condition and avoidance of exposure; and
- Permanent multiple chemical sensitivity, after substantial or intense exposure, escalation of symptoms (sometimes, but not always with clinical correlates) and spreading of effects to other chemical exposures.

<http://members.ozemail.com.au/~actall/Drs%20Articles.htm>

There is mention in studies of Stages of MCS, whereby one progresses through the stages of MCS.

Taken from William J. Meggs, M.D., Ph.D

STAGE ZERO -- TOLERANCE: is what it appears to be, the ability of a person to tolerate their chemical environment.

STAGE ONE -- SENSITISATION: or the irritant phase, "occurs when an individual is chemically stressed either by an acute high-dose chemical exposure, or by a chronic insidious exposure. Individuals in Stage 1 have symptoms on exposure to chemicals, but no physical findings on physical examination." Symptoms may include joint pain, muscle pain, headache, fatigue, flushing, pruritis, nausea, et al.

STAGE TWO -- INFLAMMATION: is when the chemical exposure has led to tissue inflammation, such as arthritis, vasculitis, some types of dermatitis, colitis, myositis, non-allergic asthma, multiple sclerosis and rhinitis. "It is at this stage that both findings in physical examination appear and a medical diagnosis can be given... The progression from Stage 1 to Stage 2 again follows increasing chemical exposures, and if tissue damage has not occurred, the inflammation can be reversed by removal of the chemical stimuli." When a person is in stage 2, the symptoms can be controlled through various medications if a person is not sensitive to those medications.

However, one needs to exercise caution because the medications are not a cure for chemical exposure, but rather can mask the root cause of the symptoms, allowing further subtle cell damage to occur if the chemicals are not avoided: "That is, progression between Stages 1 and 2 is a two-way process, with regression from Stage 2 to Stage 1 being possible if chemicals are avoided. The inflammation of Stage 2 can be reduced by medications such as corticosteroids and the non-steroidal anti-inflammatory agents, but these agents are not a curative. If the chemical stimuli are not removed, there is immediate relapse of inflammation with discontinuation of anti-inflammatory medications. Further, these medications do not prevent the progression from Stage 2 to Stage 3."

STAGE THREE -- TISSUE AND ORGAN DETERIORATION: is when chronic inflammation caused by chemical exposure has finally led to tissue damage such as nerve damage, kidney damage, liver damage, lung damage, autoimmune damage, etc. This stage is irreversible: "Unfortunately, once tissue is damaged there is little hope in current medical practice for reversal, and organ function is lost." This doesn't mean it's time to throw in the towel. It is a point where patients need to carefully re-evaluate their situation and further examine their environment for possible contributing factors. They then need to adjust by making the necessary lifestyle changes to try to prevent sill worse damage from occurring. It is important to note here that individuals can pass throughout these apparent stages without ever having developed MCS, or even without making a mental connection to chronic chemical exposure in their environment.

There are four stages listed on the website below:

<http://www.nettally.com/prusty/forma.htm>

No matter what these stages and phases are called, they should be uniform as to identify easily what stage the patient is in, so that appropriate advice and treatment protocol can be implemented.

Page 9 Notes: Unfortunately, this lack of agreement on the underlying cause and pathogenesis of MCS and subsequent lack of agreement on an operational definition of MCS has been a serious hindrance to scientific analysis/ investigation and clinical recognition of the condition.

People with MCS couldn't agree more. Just because medical science does not have answers, should not mean that it is not recognised or patients have the right to medical care. This is true of many illnesses over the years, including MS, Chronic Fatigue Syndrome, or Gulf War Syndrome, where the condition was viewed as psychotic; and sufferers went without treatment or recognition for many years.

Page 11 and 16 – similarities to other conditions. Notes: There are a number of syndromes (i.e. symptom complexes) that appear to overlap with the clinical features proposed for the category of MCS such as CFS and FM. The relationship between these entities and MCS syndrome is unclear at present and this creates difficulty with diagnostic categorisation.

My response: It is of my own personal opinion, after seeking treatment for the condition MCS from many health care professionals, that MCS is likened to other conditions, simply because these professionals have no information on MCS. Many people are diagnosed with depression simply because they state they are depressed about their newfound non lifestyle, and given antidepressants, which are of no benefit to a person with MCS. The muscle aches that are experienced by a person with MCS, is likened to Fibromyalgia, and the fatigue, well associated with Chronic Fatigue Syndrome. While a person with MCS may have weak muscles and overwhelming fatigue, it should not be likened to these conditions, as they are treated very differently. As mentioned previously professionals who do not identify that a patient has MCS in the first stages, actually interferes with the process of treatment, as, if intervention is not implemented early, the suffer travels through the fore mentioned stages or phases of MCS very quickly.

Page 13 Notes: Studies suggest that “inducing” chemicals may not necessarily be the same as those that thereafter “trigger” symptoms in susceptible individuals. This distinction may explain the difficulty in linking the known toxicity of a chemical to the understanding of symptoms and importantly, establishing effective treatment regimes. Reported chemical triggering agents for MCS are diverse and often chemically unrelated. Research reports suggest that there is likely to be a psychogenic component in the aetiology of MCS. QUESTION: are there additional triggers identified in MCS?

My response: There is no psychogenic cause or component to MCS and I shall answer this question from a personal perspective. When you are exposed to a trigger, we shall say pesticides, that has known to in the past constrict your airways, deaden your legs, cause severe heart pain, make you agitated and experience brain fog, make you dizzy – almost passing out, and then place you into a deep sleep, no matter where you are, including

driving your car... your flight/ fight response works each and every time you are near the same substance. This is not because you are psychotic; it is simply because you are scared of what may happen to you upon exposure. Likened to Pavlov's conditioning, however it is not the same. It is not a conditioned response, it is genuine fear. My condition has improved over 10 years, and I do not get as severe reaction, in comparison to when I was first diagnosed, however...I still react and I cannot tell not what, but when my reaction will be, as it is often delayed, and therefore how can it be a conditioned response when the reaction is delayed?

Triggering chemical agents unrelated to the original exposure is known as the spreading phenomenon, a reality of MCS that cannot be explained. It is well discussed in the books by Dr Doris Rapp. www.drrapp.com

It was clear to me when I first developed MCS, what caused my MCS, and that was from living next to a contaminated site in Perth. I became intolerant to the chemicals that I was over exposed to, from there; I became more and more intolerant to other unrelated chemicals. This is due to the toxic burden and overload in our bodies, and the developing inability to be able to detoxify chemicals as explained by Dr Martin Pall.

Page 16 Notes: There is a wide spectrum of intolerance/irritation from smells and fumes in the general population and it is not possible to draw any clear dividing line to delineate patients who might fall into the category of the proposed classification.

My response: Anybody that has MCS will tell you that there is a clear dividing line, simply because the people who do not like the smell of something do not have the adverse health affects or reactions that people with MCS suffer. I don't like the smell of bad body odour, but this smell does not cause a reaction unless of course the body odour being smelt is the perspiration of a chemical odour that the person uses to which I maybe intolerant to. I.e. perfume or sulphur foods. This confusion has been caused through inappropriate records stating that patients are intolerant to the 'smell' of something, versus the chemical as stated previously.

Page 16 Notes: A more recent Canadian survey reported a female bias among MCS subjects, and also reported that MCS (together with other medically unexplained physical symptoms) were more common in low income households (Park and Knudson 2007).

My Response: Of a personal opinion, the female biases maybe due to many of the chemicals that are used in society are endocrine disruptors, which simply affect women more than men. They act upon the hormones in women that men do not have. As previously discussed, the collection of semen is a useful tool in diagnosing the effects of chemical exposure in men but women will note an easily identifiable source of disruption to their hormones via irregular menstruation or other difficulties.

Before the hypothesis of environmental hormone disruptors was recognised, pioneers in environmental medicine had noted that patients with MCS were intolerant to vegetables stored in odorous plastic packaging or containers. (27, 28) People with MCS are intolerant to many endocrine disruptors, including pesticides, perfumes, industrial chemicals, solvents, cleaners, plastic and cosmetics. (29) Low-level exposures to EDC's are inducing symptoms which are often debilitating, and victims severely affected are often unable to function in the public environment. (30)

New studies have shown a direct link to EDC's damaging human cells. A common weed killer in the U.S., already suspected of causing sexual abnormalities in frogs and fish, has now been found to alter hormonal signaling in human cells. The UCSF study is the first to identify its full effect on human cells. (31, 32)

Page 30 Notes: In contrast, no evidence of accumulation of toxic chemicals in MCS subjects has been found.

My response: Please note the above records of pesticide being found in patient's blood & semen.

Page 45 Notes: A lack of authoritative published research specifically related to MCS. Page 45

My response: There is a webpage dedicated to research on MCS that lists peer reviewed articles.

<http://www.mcsrr.org/resources/bibliography/index.html>

5.3.1 Initial Presentation States: MCS is a condition with a diverse range of symptoms but with no agreed distinguishing signs.

My response: There are distinguishing signs; they are noted on many resource centre websites, studies and doctors notes. I am positive other submissions will contain these.

5.3.1 States: Few, if any, people who are subsequently considered to have MCS, present initially with a claim that their illness has followed exposure to chemicals.

My response: Where was this information obtained? It is clearly untrue. As mentioned above - many people who have MCS in Western Australia, developed it after living or working in or near a toxic environment. (Alcoa, Atlas Tip Site and The Kimberleys)

My Final Notes: Focusing on the psychological aspect of MCS is only going to waste more time addressing the needs of people with MCS - many sufferers have been known to be suicidal. Many people can no longer live within part of society which is a basic human right. I have had MCS for almost 10 years, and there have not been many Doctors, or individuals who have heard of this condition, let alone treat it. We are left to research & battle on, with ridicule & misinformation provided about the condition.

Australian authorities have had little or no pro-active policy on this growing public health concern. The Commonwealth Department of Health and Ageing believes that there is insufficient evidence upon which to base a strategy for MCS. (33) The Commonwealth Department of Health and Ageing (DoHA) states MCS has been debated in professional circles for many years, without consensus. The New South Wales Department of Health considers providing special facilities to be inappropriate at this time. (34)

Our previous health minister in Western Australia, Mr. John Day in 2000 stated to me via letter, that MCS is not a recognised medical diagnosis. Mr. John Kobelke simply referred to MCS as a controversial illness without any other advice or assistance.

Associate Professor Chris Winder is a consultant in chemical safety he states: “Whilst MCS is still a controversial condition, it is sufficiently well established in the scientific and medical literature to be acceptable as a medical entity. Further, in NSW at least, it is recognised as a compensable injury.”

If MCS is viewed as legitimate disability; government departments must review health legislation in order to avoid future litigation. This condition has been in debate for far too long, government attention is urgently required to recognise MCS, develop strategies to reduce the illness and the symptoms, and to provide some basic care rights - after all, that is the goal of public health.

Yours Sincerely,
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