

ASEHA Qld Inc

ALLERGY, SENSITIVITY & ENVIRONMENTAL HEALTH ASSOCIATION Qld Inc
PO BOX 96 MARGATE QLD 4019

ABN: 63906425543

Phone/Fax: 07 3284 8742

Email: asehaqld@powerup.com.au

Website: www.asehaqld.org.au

A volunteer community organisation providing support for people with allergy, food and chemical sensitivity

A participating organisation of National Toxics Network

17th May 2006

QUESTIONNAIRE - MULTIPLE CHEMICAL SENSITIVITY

Prepared by Dr Sharyn Martin, PhD and Dorothy M. Bowes for ASEHA Qld Inc May 2006

Prepared For The BMP Healthcare Consulting (BMP) on behalf of the Office of Chemical Safety Australian Government

Name: Dorothy Bowes and Dr Sharyn Martin

Name of organisation: ASHEA Qld

Contact details: Dorothy Bowes ASEHA President 07 3284 8742

Category of interest: Support Group, Researchers & Individuals experiencing MCS

As ASEHA representatives and MCS sufferers, Dorothy Bowes and Sharyn Martin have answered the survey questions drawing on credible scientific and medical references. Incorporated are real problems and actual experiences that ASEHA has encountered through its advocacy work and communications with ASEHA members and the public. MCS has far reaching implications if left undiagnosed and untreated as it not only affects the health of the individual, it also affects that person and families lifestyle, financial situation, ability to socialise, ability to support oneself or family, ability to access and utilise facilities such as hospitals, schools, libraries, shopping centres, health care facilities etc.

ASEHA has prepared 16 recommendations, p26, that we feel would progress the issues raised in answering these questions. We have included the main issues for MCS sufferers from this document; the most urgent of these is access to appropriate medical practitioners and health care, hospitals and appropriate housing.

We anticipate that the body of scientific and medical evidence combined with personal experiences of MCS individuals will compel the Australian Government to further research MCS and implement further measures to address chemical regulation and usage.

LIST OF APPENDICES:

APPENDIX A. MCS Definitions

APPENDIX B. EHP Supplement Volume 105 Supplement 2, March 1997. Experimental Approaches to Chemical Sensitivity

APPENDIX C. Recommended guidance notes for physicians (Ashford & Miller. 1998).

APPENDIX D. MCS CASE HISTORIES

APPENDIX E. WHO Bangkok Charter for Health Promotion in a Globalised World

Dorothy M. Bowes (Mrs)
President

EXPERIENCE AND DIAGNOSIS

WHAT HAS BEEN YOUR EXPERIENCE WITH MCS

What do you consider to be the authoritative evidence for recognising the existence of MCS?

- Available /accessible evidence

Over the last two decades researchers have been building on and refining the criteria set out by Cullen in 1987. The latest of which is Lacoura et al, 2005, who is attempting to define criteria that can be used to differentially diagnosis individuals suspected of having MCS.

The following table summaries some of the major research and information on the recognition of MCS.

<p>MCS Criteria/Case Definitions:</p> <p>Contributions to the understanding and refinement of diagnostic criteria for MCS.</p> <p>For a summary of the definitions proposed for MCS since 1985, refer to the Danish Report on MCS Silberschmidt M, 2005 and Appendix A of this document.</p>	<p>Cullen, Mark R. 1987. The Worker with multiple chemical sensitivities: an overview. Occupational Medicine: State of the Art Reviews. 2 (4): October/December. pp.655-661.</p> <p>Ashford, N and Miller, C. 1992. Case definitions for Multiple Chemical Sensitivity. In Multiple Chemical Sensitivities: A Workshop. National Academy Press. Washington, DC. pp.41-45</p> <p>Bartha, Liliane. 1999. Multiple Chemical Sensitivity: A 1999 consensus. Archives of Environmental Health. 54(3): May/June pp.147-149</p> <p>Lacoura,Thomas Zunderb,Klaus Schmidtkec,Peter Vaithd,Carl Scheidta,Michael (2005) Multiple Chemical Sensitivity Syndrome (MCS) – suggestions for an extension of the US MCS-case definition Int. J. Hyg. Environ.-Health 208 141–151</p>
<p>Reference Books written by specialists in Environmental Medicine covering all aspects of multiple chemical sensitivity</p> <p>A selection of major researchers of MCS are Rea WJ Ashford NA Miller CS Meggs WJ Ross GH Some of their papers are listed in the references.</p>	<p>Rea, Dr W J. (1998) Chemical Sensitivity. Vols 1 - 4. CRC Press, Boca Raton, Fla. v. 1 - principles and mechanisms v. 2 - sources of total body load v. 3 - clinical manifestations of pollutant overload v. 4 - Tools of diagnosis and methods of treatment</p> <p>Ashford, N.A. and C.S. Miller. 1992. Case Definitions for Multiple Chemical Sensitivity. In Multiple Chemical Sensitivities: Addendum to Biologic Markers in Immunotoxicology. Anonymous National Academy Press, Washington, D.C. 41-63.</p> <p>Ashford, N.A. and C.S. Miller. 1998. Chemical Exposures: Low Levels and High Stakes, 2nd edition. Wiley & Sons, New York.</p>
<p>Australian Occupational Health & Safety Literature</p> <p>Chemical sensitisation to some substances is validated in OH&S legislation and policy. Avoidance as a management strategy is also validated</p> <p>While this legislation refers to the occupational setting, MCS can also develop in</p> <ul style="list-style-type: none"> • occupants of tight buildings (office workers, school children) • members of communities where the air or water has been contaminated by chemicals • individuals who have had 	<p>Sensitisation and low level exposures validated</p> <p><u>Chapter 12 Sensitisers p. 17</u></p> <ul style="list-style-type: none"> ◆ 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. (NOHSC. 1995) www.nohsc.gov.au <p>Avoidance validated</p> <p><u>Chapter 11 Effects on the skin p. 16</u></p> <ul style="list-style-type: none"> ◆ 11.1 some substances can readily penetrate the skin and this method of exposure can pose a far greater danger than

<p>personal and unique exposures to various chemicals in domestic indoor air, pesticides, drugs, and consumer products</p> <p>Ashford & Miller, 1991; Bell IR, 1997; Rea WJ, 1998; Davidoff AL and Keyl PM, 1996.</p> <p>Similar legislation and policy exists in workplace legislation in other countries e.g. UK</p>	<p>inhalation exposure;</p> <ul style="list-style-type: none"> ◆ 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. <p>This Australian OHS literature is available online www.nohsc.gov.au</p> <p>The UK Department of Work and Pensions Decision Makers Guide volume 11, chapter 66 Industrial accidents defines sensitisation and recognises incapacity due to chemical sensitisation. www.dwp.gov.uk/publications/dwp/dmq</p>
<p>History of MCS. In 1991 Hilemann filed a special report on MCS in Chemical & Engineering News. The report gives a historical overview of MCS including milestones in support of its recognition from 1951 to 1991 when the report was prepared.</p>	<p>Hileman, Bette. 1991. Multiple Chemical Sensitivity. Chemical & Engineering News. 69(29): 26 - 42.</p>
<p>Toxicology literature</p>	<p>For example Casarett & Doull's Toxicology: A Basic Science of Poisons. Chapter 1, Principles of Toxicology defines chemical sensitivity, chemical allergy, models of sensitisation and various mechanisms of toxicity. Many chemicals are known human allergens e.g. pyrethrum. Amdur et al 1991; Klaasen et al 1995.</p>
<p>Research centres and Institutes such as the</p> <ul style="list-style-type: none"> • Nova Scotia Environmental Health Centre, Canada • Dallas Environmental Health Centre and • US National Institute of Environmental Health Sciences (NIEHS). 	<p>Nova Scotia Environmental Health Centre is a dedicated facility for environmental induced disease such as MCS www.cdha.nshealth.ca/facilities/nsehc It is run by the Canadian Government.</p> <p>Environmental Health Center, Dallas, Texas http://www.ehcd.com/</p> <p>US NIEHS Publications such as Environmental Health Perspectives http://ehp.niehs.nih.gov/ In 1997 a supplement Issue on Chemical Sensitivity was produced - EHP Supplement Volume 105 Supplement 2, March 1997. See Appendix B of this document for a list of papers in this issue.</p>
<p>MCS recognition. Germany has become the first country to formally recognise MCS by its inclusion within the German version of the International Statistical Classification of Diseases and Related Health Problems, ICD-10-SGB-V.</p>	<p>Deutschen Institut für Medizinische Dokumentation und Information (DIMDI), Internationale statistische Klassifikation der Krankheiten und verwandter Gesundheitsprobleme, 10 Revision, 2000.</p> <p>German Institute for Medical Documentation and Information, http://www.dimdi.de Published in November, 2000, by the German Institute of Medical Documentation and Information, DIMDI, by order of the Federal Ministry for Health.</p>
<p>US and US Government Recognition</p> <p>MCS Referrals & Resources list where MCS has been recognised in the USA.</p> <p>Interagency Workgroup on MCS (US ATSDR)</p> <p>The US CDC is also gathering</p>	<p>Public Health Issues in Medical Evaluation and Care of MCS Patients www.web.health.gov/environment/MCS/v.htm</p> <p>MCS Referrals & Resources: Available online at www.mcsrr.org/</p> <p>US Government Interagency Workgroup on MCS. 1998. Pre-decisional draft report. US Agency for Toxic Substances and Disease Registry. www.atsdr.gov</p> <p>The US CDC exposure reports (1-3) can be found on the CDC website. These are ongoing in tandem with NHANES which is a dietary and nutrition survey to compliment the chemical exposure</p>

<p>data on the body burden of chemicals (NHEXAS).</p>	<p>(NHEXAS) survey www.cdc.gov</p>
<p>Successful litigation. In the United States the legal ramifications of MCS are far ahead of the science and MCS has been widely recognised in policy arenas. Recent reports of individuals with fragrance sensitivity pursuing compensation in the Courts indicates that MCS exists at Law.</p> <p>Fragrance sensitivity is a recognised disability in the USA under their Americans with a Disability Act.</p>	<p>Fragrances are complex mixtures of chemicals, many of which are solvents, sensitisers, carcinogens, endocrine disruptors. Data exists to substantiate the litigation and harmful nature of fragrances. www.ehp.niehs.gov/docs/1998/106-12/focus.html www.fpinva.org ; www.ehnca.org.ehnhompg/takheart.htm www.ewg.org/reports/skindeep/, www.dfsan.fda.gov</p> <p>A Scottish man was jailed for 14 months for deliberately exposing his wife to a fragranced product in March 2000. BBC News. Scotland. www.news.bbc.co.uk/1/hi/uk/scotland/647688.stm</p> <p>Editors former nanny settles fumes case in NY. Planet Ark 21/10/04 www.planetark.com/avantgo/dailynewsstory.cfm?newsid=27776</p> <p>Wife arrested for raising a big stink. Miami Herald 11/05/03 www.miami.com/mld/miamiherald/news/state/5827667.htm</p> <p>Many cases involving chemicals settle out of court to avoid precedents being set. Cases settled in this way usually involve confidentiality clauses to ensure that case details do not become public. Individuals using anti discrimination processes are gagged by confidentiality provisions as well.</p>
<p>Disability Recognition US Government recognises MCS as a disability under the Americans with a Disability Act and provides assistance to agencies to make available information about MCS and accommodate sufferers in the workplace, in education and housing.</p> <p>The US Department of Housing and Urban Development (HUD) and the Social Security Administration grant affected individuals protection under the Social Security Act and the Fair Housing Act. HUD protects individuals under federal housing discrimination laws to allow e.g a pesticide free zone around a person's home. (Dean, 2002)</p>	<p>Some of the regulatory and policy actions provide criteria and terms to define MCS.</p> <p>Arizona University. Arizona Technical Assistance Program. http://www.nau.edu/ihd/aztap</p> <p>Job Accommodation Network http://www.jan.wvu.edu/media/atoz.htm.</p> <p>Students with MCS: An accommodation challenge. www.acenet.edu/Programs/HEATH.MCS.html</p> <p>University of Minnesota Disability Service www.disserv.stu.umn.edu/TC/Admin/MCS-Guidelines.html</p> <p>Fragrances should not be discernable any more than one meter away from the wearer or point of application</p>
<p>Dermatologists</p>	<p>Patch testing (skin) for various chemicals e.g. fragrance allergy www.dermnetnz.org</p>
<p>Australian Human Rights & Equal Opportunities Commission</p>	<p>MCS is a disability recognised by the HREOC (personal correspondence)</p>
<p>Fragrance and Pesticide Free Facilities (Recognition of Potential Harm)</p>	
<p>US Fragrance free hospital policies, and reduction in Volatile Organic Compounds</p>	<p>Weinhold, B. 2002. Making Health Care Healthier: a prescription for change. <i>Environmental Health Perspectives</i> 109(8):A370-377;</p> <p>US Fragrance free hospitals: www.ehnca.org/ehnhompg/takheart.htm</p>

<p>Canadian fragrance free hospital policies</p> <p>Halifax no scents policies</p>	<p>Capital Health. QEII Health Sciences Centre. Patient and visitor information www.cdha.nshealth.ca/facilitiesqe2hsc/patientsandvisitors/index.html</p> <p>Nova Scotia Environmental Health Center www.cfha.nshealth.ca/facilities/nsehc/index.html</p> <p>Halifax Metro Transit Riders Guide www.halifax.ca/metrotransit p.3 Scents. Passengers are asked to respect the comfort of others who are sensitive to fragrances and consider a 'scent free' environment.</p> <p>Halifax Regional Municipality. Advisory Committee for Persons with Disabilities 2. 2002. www.halifax.ca-boards.abilcom.2002abil-acfpwd020916.pdf.url</p>
<p>Pesticide free hospitals.</p> <p>New York Attorney General report on pesticide use in hospitals</p> <p>New York Attorney General's report on pest control and childhood risk</p>	<p>Healthy Hospitals: Controlling pests without harmful pesticides. Report written by Beyond pesticides www.beyondpesticides.org and Health Care Without Harm which is an international coalition of hospitals and health care systems, medical professionals, community groups, health-affected constituencies, labour unions, environmental and environmental health organizations and religious groups. Its mission is to transform the health care industry worldwide, without compromising patient safety or care, so that it is ecologically sustainable and no longer a source of harm to public health and the environment. www.noharm.org</p> <p>The NY Attorney General reported on pesticide use in hospitals. The role of pesticides in the reduction of vermin infestation was acknowledged as was the toxicity of pesticides which can also have harmful effects on humans. The principle recommendation of the report was that all hospitals should adopt the least toxic pest management policies and practices and adopt Integrated Pest Management programs. www.oag.state.ny.us/environment/hospital95.html</p> <p>The NY Attorney General in 2002 developed an evidence-based approach for addressing the problem of pesticide toxicity in New York State. The report, <i>Pest Control in Public Housing, Schools and Parks: Urban Children at Risk</i> is based on a detailed survey of pest control practices in the public housing, schools and parks of five major cities across New York State. www.oag.ny.us/environment/pest_control_public/housing.pdf</p>

What specific symptoms and signs were used to determine the presence of MCS for you?

The signs and symptoms pertaining to MCS are complex and related to multiple organs (see Table 'Symptoms reported by chemically sensitive individuals' (Bowes DM, 1997)). The predominating symptoms in MCS are generally CNS specific, other symptoms and signs maybe a result of pre-existing conditions such as asthma, allergy or part of the chronic ill health that develops with MCS. Symptoms and signs related to specific exposures may also be influenced by the substance - eg pesticide, perfume, paint exposure and can be different. Symptoms related to a specific acute exposure are generally more severe than those experienced at other times.

Saito Mariko et al, 2005 investigated the symptom profile of patients with MCS in actual life. They used a computerized Ecological Momentary Assessment (EMA) technique to record answers to a predefined interview protocol under both random prompts and when hypersensitive symptoms occurred. This was combined with passive air sampling throughout the week's testing period and active sampling when hypersensitivity symptoms appeared. MCS patients were compared with a control group. They found that 11 of 17 physical symptoms and all 4 mood subscales were significantly aggravated in patient initiated responses (when hypersensitivity symptoms occur). During hypersensitivity periods symptoms most often reported in MCS patients were concentration problems, forgetfulness, sore throat, headache, muscular pain, nausea, breathlessness, eye irritation, dizziness/vertigo, stuffy and runny nose and palpitations. In addition 3 negative mood scales were

significantly higher and 1 positive mood scale significantly lower. 'Causative chemicals' were detected in 79% of the patient air samples. Some of the most predominant chemicals were formaldehyde, acetaldehyde, acetone and xylene. There was no significant difference between MCS patients and controls in interviews based on random prompts. They concluded from their study that MCS patients do not have either somatic or psychologic symptoms under chemical free conditions and symptoms may be provoked only when exposed to chemicals.

Signs and symptoms pertaining to MCS are defined in Rea, WJ, 1998, Vol4, Ashford & Miller, 1998, Appendix C: p371. The paper by Lacoura et al., 2005, on suggestions for an extension of the US MCS-case definition has reviewed original literature of symptom-profiles in patients with self-reported MCS.

Other relevant references include: Ziem and McTamney 1997; MCS Referrals & Resources www.mcsrr.org; Joffres et al 2001.

Symptoms taken from ASEHA workshop respondents, June 1995. (Bowes, D M., 1997)

Body system	Symptoms
CNS/ Neurological	Migraine; Headache; mental confusion, memory impairment, emotional lability; cannot stay awake; sudden acute fatigue; chronic fatigue; dizziness; loss of balance; poor coordination; poor concentration; speech impairment; depression; insomnia; hyperactivity; ADD; learning disabilities; neuralgia; lock jaw (TMJ)
Neuromuscular	Tic; seizures; tremors; muscle cramps; muscular spasms;
Sensory	Ears:- Tinnitus; itchy ears; ear ache; blocked ears; Eyes:-dry, itchy eyes; eye pain; weepy eyes; sore eyes; lumps in eyes; Vision:- visual disturbances; blurred vision
Integumentary	Rashes; skin irritation; dark circles under eyes; spontaneous bruising
Inflammatory/ mucosal	Throat swelling; laryngitis; dry & sore throat; mouth ulceration; tongue swelling; bloodshot eyes; swollen gums
Respiratory	Sneezing; coughing; asthma; wheezing; shortness of breath; breathing difficulty; respiratory irritation; rhinitis; sinusitis
Gastrointestinal	Stomach cramps; constipation; diarrhoea; incontinence (anal leakage); vomiting; nausea; decreased liver function; jaundice; hepatomegaly; splenomegaly
Skeletal / Articular	Joint pain; reactive arthritis
Metabolic disorders	Toxic acidity; food intolerance; chronic food addiction; intolerance to medications; Inability to tolerate heat or cold; universal reactor;
Genitourinary	Incontinence; kidney pain; increased frequency of urination; urgency of urination; painful urination; nocturnal urination; bedwetting
Cardiovascular/ circulatory	Toxic poisoning shock (coldness); mitral valve prolapse; palpitations; chest pain of no known origin; anaphylactic shock; localised swelling;
Endocrine	Thyroid imbalance; PMT symptoms

Are you aware of the criteria health care providers (doctors and other practitioners) use to establish the diagnosis of MCS? For example: are all of the Cullen criteria necessary to be fulfilled to establish the diagnosis?

To determine the presence MCS Ashford & Miller (1998) state 'meticulous history taking is important in making a diagnosis'. Important aspects are a comprehensive Health history and Occupational exposure history - occupational, tight building or community exposure. (Rea, W J. 1998 vol. 4; Ashford & Miller, 1998)

Each practitioner will vary in approach according to their specialty, research and experience with MCS
In general the criteria used to establish MCS are

1. chronic condition (usually > 6 months)
2. symptoms recur reproducibly
3. multiple organ systems involved
4. response is to low levels of multiple unrelated chemicals
5. condition improves or resolved when incitants removed

The Cullen criteria were proposed in 1987 and since that time problems have been highlighted as to the vast mixture of chemicals that people are exposed to on a daily basis (Carpenter DO et al, 2002). Several surveys indicate that between 15 – 30% of the general population report sensitivity or irritant value to chemicals, including fragranced products (see prevalence data table). The degree to which this has developed, the number of chemicals involved and to what degree it interferes with a normal functioning existence seems to be the point at which MCS is diagnosed. MCS probably represents the extreme end of a continuum of health problems that are occurring in response to everyday chemicals (Davidoff AL & Keyl PM, 1996).

Claudia Miller (Ashford & Miller, 1998) proposed the term toxicant induced loss of tolerance and determined that the gold standard for diagnosing a chemically sensitive individual is the environmental control unit (Chemical free environment). Diagnosis can be made by removing individuals from toxins and then challenging them with specific chemicals. (Ashford N and Miller C. 1998)

MCS/hypersensitivity to chemicals has also been associated with allergy and other disorders such as CFS & Fibromyalgia (Meggs et al, 1996; Caress and Steineman, 2005; Lacour et al, 2005). It has been suggested that allergy maybe 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. Studies by Elberling J et al, 2005a & 2005b have found that IgE mediated allergic mechanisms do not play a major role in the development of the eye and airway 'hypersensitivity' symptoms to chemicals found in fragranced products, laser printers, drying paint, car exhaust and newspapers and fragranced products.

A practitioner who is aware of these factors may be able to circumvent progression to MCS by advising patients of risk factors and avoidance strategies that can alleviate current symptoms and avoid worsening of their condition. Ashford and Miller, 1998, developed physician guidance notes on the steps involved when dealing with a potential chemically sensitivity patient. See Appendix C of this document for these guidelines.

Were any diagnostic tests used to confirm the diagnosis of your MCS?

Vol 4 of Dr WJ Rea books outlines the tools of diagnosis and methods of treatment of MCS. Rea, W J, 1998.

Double blind challenges with the triggering substances/s is a gold standard for testing, but requires an Environmental Control Unit and are therefore performed very rarely. Due to the difficulties associated with testing in environmental controlled units, Saito Mariko et al, 2005 investigated the use of a computerized Ecological Momentary Assessment (EMA) technique to record answers to a predefined interview protocol under both random prompts and when hypersensitive symptoms occur. This was combined with active air sampling during the hypersensitivity period to determine the chemical causing the hypersensitivity reaction. In their study using a specified set of chemicals to test for, causative chemicals were detected in 79% of MCS patients.

No single test has yet been developed that has proven 100% effective in diagnosing all MCS patients. The following tests have been found by the Chemical Injury Information Network (CIIN) www.ciin.org to be helpful in documenting biologic markers for MCS:

To detect chemicals, their metabolites, or heavy metals in the body:

1. Blood tests for toxic substances such as VOCs and pesticides.
2. Urine tests.
3. Fat biopsies.

Immune system testing:

1. Antibody Assay testing for chemical antibody formation.
2. Activated Lymphocyte Profiles.
3. Autoimmune Disease Profiles.
4. Autoimmune Profiles for nervous system disorders.
5. Allergy testing for foods, molds, pollens, and chemicals. RAST and total IgE can be used as partial indicators of inhalant, food and chemical sensitivities. Immunoglobulins A, G, D, E and M and their immune

complexes, opo-sins and phagocytic index may be appropriate, especially for those experiencing recurrent infections.

Metabolic testing: Porphyria

Neuropsychological testing:

1. Complete neurological examination. 2. Positron Emission Tomography (PET) scans. 3. Quantified Electroencephalogram (qEEG) with evoked potentials. 4. Single Photon Emission Computed Tomography (SPECT) scans. 5. Neurobehavioral testing.

Other testing considerations:

1. Enzyme testing for cholinesterases, antioxidants, liver, etc. 2. Amino acids profiles: Standard Panel and Neuropsychiatric Panel. 3. Rhinolaryngoscopic examination to check for damage in the nasal passages. 4. Conditions and disorders associated with specific chemical exposures such as aplastic anemia, pulmonary function tests, heart monitoring, detailed and sensitive testing for various organ and/or system damage, etc.

Chemical Injury Information Network (CIIN) www.ciin.org

Other tests used by Rea WJ, 1998 and Ashford & Miller, 1998) include:

- ◆ Provocation by oral, intradermal, or inhaled challenge is used to confirm the diagnosis.
- ◆ Analysis of biological detoxification systems e.g. super-oxide dismutase.
- ◆ Liver function tests.
- ◆ Assessment of nutritional status e.g. vitamins, minerals, amino acids and fatty acids.'

Food Testing: The grand elimination diet and challenge procedure (Loblay, R and Swain, A. 1986) is used routinely in the allergy clinic at the Royal Prince Alfred Hospital in Sydney. <http://www.cs.nsw.gov.au/rpa/Allergy/default.htm> Foods contain not only allergens but naturally occurring phenolic compounds and food additives which affect health and need to be avoided in the diet. Natural phenolic compounds can be modulated by pesticide residues and can further affect the health of chemically sensitive patients (Mieir DO et al, 1999). Organic (chemical free) foods are a necessary part of the treatment of chemically sensitive individuals. Organic diets have also been found to significantly reduce children's dietary exposure to pesticides (Chenseng L et al, 2006)

The potential role of genetics in the development of MCS is being uncovered by McKeown-Eyssen et al, 2004. In an epidemiological study they found several genetic differences between cases and controls in genes involved in detoxifying contaminants. The study also found that women with a specific combination of forms of two separate genes for CYP2D6 (Cytochrome P450 2D6) and NAT2 (N-acetyltransferases) were 18 times more likely to have MCS. These women were homozygous for genotypes encoding the enzymes CYP2D6 and the NAT2 'rapid acetylator' form. CYP2D6 encodes for enzymes that detoxifies many toxic chemicals as well as pharmaceutical drugs by making them more water soluble. NAT2 encodes for enzymes that metabolise drugs and toxic chemicals including aromatic amines many of which are known carcinogens.

A specific genetic polymorphism of a gene encoding the enzyme PON1 has been implicated in the occurrence of chronic neurological symptoms in Gulf War veterans. The enzyme PON1 metabolises organophosphates. Haley, R. W et al, 1999; Furlong, C, 2000.

What do you consider were the factors that contributed to you getting MCS?

Factors contributing to the development of MCS are diverse and are dependent on the individual's exposure history, the sensitising episode, age, health etc. There are some occupations where workers are at greater risk due to the nature of the materials they work with on a daily basis, such as spray painters, solvent workers &, hairdressers. Allergy/asthma (nasal and respiratory allergy) predisposes to chemical sensitivity Meggs, W J (1999). MCS is a disease that probably everyone is susceptible to given a higher enough load but those with a predisposition are more easily sensitised with less exposure. Major reference materials on MCS listed in this document expand on the number and types of triggers involved in the development of MCS as well as the diagnostic tests that have been used.

Some individuals are exposed to multiple chemicals or can be exposed to more than one chemical splash or spill (Ziem, G. 1999). The mixtures of chemicals individuals are exposed to every day may intensify the problems caused by chemical exposure. (Carpenter O et al, 2002). Sensitisation to these mixtures of chemicals can be the result of an acute exposure or low level chronic exposures. Once

sensitised symptoms may be triggered by low levels of previously tolerated chemical inhalants, foods or drugs (Miller C et al, 1997).

Major chemical Triggers of MCS

- Pesticides,
- Fragrances/ Fragranced products,
- Solvents,
- Petrochemicals,
- Natural gas,
- New carpet,
- Renovation materials (Ex. MDF, particle board, chipboard),
- Adhesives/ glues,
- Fiberglass,
- Carbonless copy paper,
- Fabric softener,
- Formaldehyde,
- Glutaraldehyde,
- Cleaning agents – Ex Carpet shampoo,
- Isocyanates,
- Combustion products (Ex smoke from fires, poorly ventilated gas heaters),
- Medications (Ex antibiotics, anaesthetics),
- Terpenes and terpenoids,
- Personal Care Products. Including cosmetics, deodorants, soaps, shampoo, perfumes etc,
- Household aerosols,

Ziem & Mc Tamney. 1997; Ashford and Miller 1998; Rea, 1994; Miller CS and Mitzel, HC, 1995.; Silberschmidt, M. 2005.; Fisher, B. 1998.; www.ewg.org/reports.skindeep/ ; Ziem, G. 1999; Ashford and Miller (1998)

Environments and settings where chemical sensitisation can occur.

<p>Occupational</p> <p>Exposure levels of chemicals established for the occupational environment may not prevent chemical injury and do not accommodate sensitive individuals. These are set for 'nearly all workers'. www.nohsc.gov.au</p>	<ul style="list-style-type: none"> • Individuals working with solvents etc. in research and industrial facilities • Office workers:- sick building syndrome • Chemical spills in workplaces • Workers in the petrochemical industry • Farmworkers eg using pesticides • Teachers: - felt markers and craft supplies used in schools • Hospital employees: - glutaraldehyde in hospitals and dental surgeries • Hospital and Dental employees: - latex in hospitals and dental surgeries
<p>Domestic</p> <p>Chemical sensitivity also occurs in the home. Factors known to cause this are shown in this table.</p> <p>Further, the domestic environment is not regulated as is the workplace and some individuals are subjected to back yard industries such as spray painting, motor repairs, furniture building etc. Currently there is no avenue for people to have this rectified unless they can afford to litigate.</p>	<ul style="list-style-type: none"> • Indoor Air Pollution - Sick/tight building syndrome • House painting • Home renovations • New carpet or furniture • Detergents, disinfectants, laundry products • Personal care products e.g. fragrances, hair dressing aids, aerosol products especially in a confined area (e.g. bathroom with the door closed) Silberschmidt,M. 2005. • Many consumer products have high concentrations of chemicals that can contribute to overall VOC and other toxic levels in the home (UK. Royal Commission on Environmental Pollution. 2003. 24th report. Chemicals in consumer products). • Motor oils and cleaning products • Pesticides used inside the home for pest control as well as outside in the garden and around the home exterior. Household sometimes spray lawns for pests/weeds with bare feet. Children have also

	<p>been observed playing on the freshly treated surfaces barefooted.</p>
<p>Environmental (Including public areas & buildings)</p> <p>In Honolulu a school had to be evacuated following use of pesticide on a nearby property. Boylan P. 2006. Pesticide fumes sicken children. Honolulu Advertiser. Apr.14. http://the.honoluluadvertiser.com/article/2006/Apr/14/In/FP604140362.html</p> <p>Children in farming areas are often exposed to spray drift from neighbouring properties.</p> <p>At the Australian National University it has been noted that students with MCS have difficulty accessing the disability resource unit (DSU). All users of the DSU have been asked to avoid wearing perfumed products and essential oils. www.anu.edu.au/disabilities/resourceroom.htm</p> <p>A more recent example of environmental poisoning is the Western Australian facility owned by ALCOA that has been accused by the Trade Union and Residents of causing MCS</p>	<ul style="list-style-type: none"> • Toxic fumes from industrial estates e.g. toxic waste disposal and other industrial pollutants. • Toxic emanations from dumpsites • Chemical fires e.g. pesticide storage facilities, dumps, furniture or carpet factories • Bush fires in scrub that has been treated with pesticides/herbicides, or where rubbish is involved e.g. old tyres • Pesticide programs for mosquito eradication in the urban environment - these are often applied from the air with no regard to weather conditions or wind • Herbicide programs for weed control in the urban environment - footpaths, gutters, parks, creeks & golf courses • Fire ant eradication in affected areas • Road building and re-surfacing • Paint fumes from neighbouring houses • Perfume fumes from neighbouring houses (detergents, disinfectants, laundry products, scented candles, incense etc) • Back yard industry in the residential environment • Wood smoke from solid fuel burning appliances • Motor exhaust fumes • Living in close proximity to a petrol refinery • Living in a farming area with pesticide drift and exposure
<p>Recreational</p>	<ul style="list-style-type: none"> • Swimming in a chlorinated pool • Some art and craft supplies • Sports grounds and parks recently sprayed with herbicides for weed control (School children sitting on grass freshly sprayed)
<p>Personal</p>	<ul style="list-style-type: none"> • Some substances readily cross the placenta and affect the foetus in utero e.g. DDT, dioxin • Breast milk maybe contaminated with lipophilic substances e.g. dioxin, DDT, brominated flame retardants, Teflon and be passed onto the infant. • Residues of pesticides in foods (left over from best practice use) • Food processing aids in commercially produced foods • Allergic reaction to medications such as antibiotics, anaesthetics • Cosmetics and personal care products contain known human allergens, sensitisers, carcinogens and endocrine disruptors. Products such as cosmetics, fragrances and underarm deodorants are mixtures of chemicals for which the health risk is unknown. As such products can be applied to the skin several times per day they represent a significant exposure.
<p>Medications</p>	<p>Ashford and Miller (1998) state that physicians understand 'multiple drug allergy syndrome' i.e. that a person who has had an adverse reaction to one drug is likely to react to other drugs e.g. individuals who react to penicillin are more likely to react adversely to other antibiotics. Meggs compiled a list of symptoms reported for seven well-known pharmaceuticals which corresponded to individuals exposed to various organic</p>

	<p>compounds. Meggs suggested there is a similarity between adverse drug reactions and volatile organic compounds. Medications also contain so-called 'inert' ingredients e.g. lactose gluten fillers, colourings, flavourings, preservatives and others. These can also be problematic to a chemically sensitive individual. Other problems related to medical care are ointments, lotions, gels, adhesive tape, plastics used in drips and oxygen masks and tubing, latex in gloves and for other uses.</p>
--	---

References: Weinhold, B. 2001.; Ziem, and McTamney. 1997; Silberschmidt, M. 2005.; Powell, J J et al. 1999.; Miller CS and Mitzel HC. 1995.

Case Histories documenting MCS developed can be found in Appendix D of this document.

Do you have any information on how wide spread MCS might be?

Chemical exposure and resultant MCS is not limited to the occupational environment. Ryan et al state that more than 20 million people in the USA are exposed to toxic substances in the home or workplace. For the vast majority of those people, mixtures of organic solvents are the most frequent source of exposure (Ryan et al. 1988)

Bell et al in 1997 reported a substantial proportion of various populations presenting to an occupational medicine setting reported cacosmia:

- ◆ approximately 60% of solvent exposed workers (mainly blue-collar workers)
- ◆ 30% of a sample of almost 4,000 office workers (mainly female, professional, white collar workers)
- ◆ 15-30% of college students and active, retired, elderly individuals (Bell et al. 1997)

Claudia Miller, Associate Professor of Environmental and Occupational Medicine at the University of Texas Health Sciences Centre in San Antonio, says that several studies indicate:

- ◆ 15-30% of the population report sensitivity to chemicals, including fragrances;
- ◆ 4-6% report that chemical intolerance has a major impact on their quality of life and of these
- ◆ Many Gulf War Veterans report chemical intolerances since the war, including sensitivity to fragrances. (Fisher. 1998)

In a review of MCS prevalence, Sorg in 1999 concluded that the “prevalence of severe MCS in the U.S. is 4% with greatly reduced quality of life for the patient” and stated that “Less severe problems with chemical exposures have been reported in 15–30% of the population.” (Sorg, 1999).

Several studies indicate that the incidence of allergy and chemical sensitivity is similar (Meggs et al, 1997; Caress and Steineman, 2005; Lacoura et al, 2005). Individuals with allergy often have food sensitivities and chemical sensitivities. In the study by Meggs et al, 1996 allergy and chemical sensitivity were distributed widely across age, income, race and educational groups. Simultaneous allergy and chemical sensitivity were reported by 16.9% of the population, allergy without chemical sensitivity by 16%, chemical sensitivity without allergy by 18.2% and neither condition by 48%. The conclusion of the survey was that the prevalence of sensitivity to chemical irritants is comparable to that of allergy (Meggs et al 1997). Similarly the study by Caress and Steinemann in 2005 found that of the 11.2% of participants who reported hypersensitivity to chemicals, 42% were diagnosed with asthma. Of the 14.1% of total participants diagnosed with asthma 27.2% were hypersensitive to chemicals and 7.4% had been also diagnosed with MCS.

If we can conclude from the studies by Meggs et al, 1997 and Caress and Steinemann, 2005 that the prevalence of sensitivity to chemical irritants is equivalent to that of allergy, individuals with some degree of sensitivity to chemical irritants represents a very significant percentage of the general population. Prevalence rates of chemical sensitivity from several studies from 1993 to 2005 are shown in the following table.

Chemical hypersensitivity/MCS diagnosis Prevalence Rates

MCS Prevalence Rates	Percentage of respondents	Reference source
National Academy of Science	15%	Mitchell F, ed. 1995 Multiple Chemical Sensitivity: A Scientific Overview. Atlanta: US Department of Health and Human Services, Public Health Services Agency for Toxic Substances and Disease Registry.
*California Dept Health Services	15.9%	Kreutzer R, Neutra RR, Lashuay N. 1999 Prevalence of people reporting sensitivities to chemicals in a population-based survey. Am J Epidemiol.;150:1–12.
*Atlanta, Georgia, metropolitan area	12.6%	Caress SM, Steinemann AC. 2004 The prevalence of multiple chemical sensitivities in a population based study. Am J Public Health.; 94: 746 –747.
*State of New Mexico	16%	Voorhees R. 1997 Results of Analyses of Multiple Chemical Sensitivities Questions. New Mexico Behavioral Risk Factor Surveillance Systems. New Mexico Department of Health, Office of Epidemiology;25.
Conversations with medical personnel in clinical settings	2 – 10%	Mooser SB. 1987 The epidemiology of multiple chemical sensitivities (MCS). Occup Med.;2:663–681.
Arizona study Young college students	15%	Bell IR, Schwartz GE, Peterson JM, Amend D. 1993 Self-reported illness from chemical odors in young adults without clinical syndromes or occupational exposures. Arch Environ Health.;48:6–13.
Arizona study Elderly persons	37%	Bell IR, Walsh ME, Goss A, Gersmeyer, Schwartz GE, Kanof P. 1997 Cognitive dysfunctions and disabilities in geriatric veterans with self-reported intolerance to environmental chemicals. J Chron Fatig Synd.;2:5– 42.
Rural Arizona population survey	33%	Meggs WJ, Dunn KA, Bloch RM, Goodman PE, Davidoff AL. 1996 Prevalence and nature of allergy and chemical sensitivity in a general population. Arch Environ Health. 51:275–282.
UK Military Personnel 1. Gulf War veterans deployed 2. Gulf War, not deployed 3. Bosnia War	1. 28% 2. 14% 3. 13%	Reid S, Hotopf M, Hull L, Ismail K, Unwin C and Wessely S., 2002. Reported chemical sensitivities in a health survey of United Kingdom military personnel. Occup. Environ. Med.;59:196-198doi:10.1136/oem.59.3.196
Caress and Steinemann National survey. 2005		Caress S and Steinemann A. 2005. National Prevalence of Asthma and Chemical Hypersensitivity: An Examination of Potential Overlap J Occup Environ Med.; 47:518–522
Hypersensitivity to chemicals	11.2%	
Diagnosed with MCS	7.4%	
Older adults	34%	Bell I R, Schwartz GE, Amend D, Peterson JM, Stini WA. 1994. Sensitisation to early life stress and response to chemical odors in older adults. Biol Psychiatry 35: 857-63
Older adults	17%	Bell et al. 1993. Possible time-dependent sensitisation to xenobiotics self reported illness from chemical odors, foods and opiate drugs in an older adult population Archives of Environmental Health 48:315-27
Australian Population, NSW adult health survey 2002		Australian Population, NSW adult health survey 2002
Overall hypersensitive to chemicals	24.6%	
Rural population (hypersensitive)	23.7%	
Urban population (hypersensitive)	24.8%	
Diagnosed with MCS	2.9%	

German population		Hausteiner C, Bornschein S, Hansen J, Zilker T, Forstl H. 2005. Self-reported chemical sensitivity in Germany: A population-based survey. Int. J. Hyg. Environ.-Health. 208; 271-278
Self reported sensitivity	9%	
Diagnosed MCS	0.5%	

What factors do you consider might influence the apparent gender, workplace, ethnic and geographic differences in the prevalence of the diagnosis of MCS?

Although there is an apparent bias towards women having symptoms of chemical sensitivity, in the UK military personnel prevalence study, 92% of the sample population were male. Of these 13 – 28% reported sensitivity symptoms to at least one chemical. The bias in the study maybe due to occupational exposure of military personnel to diesel fumes and pesticides (Reid et al, 2002)

On the apparent gender, workplace, ethnic and geographic differences, a paper by Davidoff AL and Keyl PL, 1996, discusses some of these issues in detail. Davidoff found that MCS individuals were diverse with respect to gender and education as did Meggs, 1996. Many of the major references cited in this document also deal with this in more detail. Identification of adverse environmental health effects requires a comprehensive exposure history and interpretation of the findings and knowledge of possible routes of exposure and common sources (Marshall L et al, 2002; Weir E, 2002)

A paper by Marshall L et al, 2002 in the Canadian Medical Journal found that “Most primary care physicians lack training in and knowledge of the clinical recognition, management and avoidance of such exposures” (*to substances such as lead, air pollutants and pesticides*). If physicians are not given sufficient education on the potential for environmentally triggered illness throughout their medical training it is not unexpected that they do not take into consideration that environmental problems frequently present as common medical problems such as headache, difficulty concentrating, fatigue etc.

Recent research indicates that there maybe a genetic predisposition for MCS involving altered biotransformation of environmental chemicals McKeown-Eyssen et al, 2004. Infants and young children are also more susceptible to some environmental toxins due to immature detoxification systems. (See ASEHA website Children’s Health Page for a list of references www.asehaqld.org.au)

Other factors involved in apparent differences are:

- ◆ State of health – obesity, diabetes
- ◆ Medications taken e.g. immune suppressants,
- ◆ Age
- ◆ Allergy/asthma sufferers - nasal and respiratory allergy predisposes to chemical sensitivity Meggs, W J (1999)
- ◆ Females have a higher level of body fat than males and accumulate lipid soluble chemicals more easily. This maybe especially important in light of the genetic differences in detoxification enzymes.
- ◆ Females are more likely to seek a diagnosis than men
- ◆ Income, geographic location & education influence health issues in low income and ethnic populations. They have less disposable income for health care and to live a healthy lifestyle, are usually poorly educated and often live close to toxic dumps, industrial or agricultural areas i.e. high pollution because rents are cheaper. They usually lack the skills to take action to improve their immediate air quality.

Do you regard MCS as somehow related to chronic fatigue syndrome?

Fatigue is a common symptom amongst those with MCS, whether the chronic fatigue came first or the MCS maybe the difference in diagnosis. There are a number of studies on the association of MCS with CFS, Fibromyalgia, food sensitivity and allergy.

Ziem and McTamney (1997) indicate there is substantial overlap between chemical sensitivity, fibromyalgia (FM) and chronic fatigue syndrome (CFS). While FM and CFS often involve chemical sensitivity, they thought that significant musculoskeletal aching and fatigue among MCS patients was interesting given the overlap in symptomatology and clinical findings between MCS, CFS and FM.

Ziem (1999) indicates that toxic injury from repeated exposures to solvents, pesticides, fragrances etc can result in impairments to immune, endocrine and nervous systems, impairments in detoxification,

energy and neurotransmitter metabolism, protein, mineral and other nutrient deficiencies and gastrointestinal changes such as candida, parasites, reduced pancreatic enzyme function, gluten intolerance, reduced Secretory IgA, adrenal insufficiency. MCS/CFS/FM appear to be different medical labels for the same condition in many cases.

Winder (1994) refers to the US CDC definition of CFS in 1988. Although a triggering infectious illness is reported in most patients with CFS, there are increasing numbers of cases being reported from individuals following exposure to chemicals. Chronic fatigue also appears to be a two stage condition where the first stage is an infection or exposure to a toxic substance. The second stage of the disorder is long term debilitation that appears to be out of proportion to the precipitating event.

Buchwaldt and Garrity (1994) compared patients with CFS/FM/MCS as they are all conditions associated with fatigue and a variety of other symptoms that appear to share many clinical and other features. They compared three patient groups and found that patients with CFS and FM frequently reported symptoms compatible with MCS. Likewise, 70% of patients with FM and 30% of patients with MCS met the criteria for CFS. Symptoms typical of each disorder are present in the other two conditions.

Aaron and Buchwald, 2001, reviewed the evidence of symptom overlap among unexplained clinical conditions such as CFS, Fibromyalgia, MCS, IBS, temporomandibular disorder (TMD), and Tension Headaches. The shared features of the unexplained clinical conditions included fatigue/pain, inconsistent demonstration of laboratory abnormalities, disability out of proportion to examination findings and association with "stress" and psychosocial factors. Their review found substantial overlap among definitions even for core symptoms and suggested that co morbidity reports between some of these conditions is not surprising. The authors also established that varying the method for defining a clinical condition produces markedly different results. In fact the diagnosis assigned to patients with one of these illnesses depends more on the chief symptoms and clinician speciality rather than actual illness. In the literature survey patients with CFS 53 – 67% reported that their illness worsens with exposure to various chemical, 55% of Fibromyalgia patients have symptoms consistent with MCS and 30% of MCS patients meet criteria for CFS. The authors suggest that it is highly probable that the spectrum and degree of co morbidity among unexplained conditions are due to a complex interplay between genes and the environment.

Clinical Practice Guidelines for CFS were developed by the Royal Australian College of Physicians in 2002. While food and environmental intolerances were not considered to be a cause of CFS it was accepted that these exacerbated CFS. Studies noting an overlap between CFS, MCS and Gulf War Syndrome were evaluated and these entities were considered highly contentious. However, Box 1.6 (Clinical Practice Guidelines for CFS, 2002), "*Evaluation of evidence for other factors proposed to contribute to the pathophysiology of CFS*" included '*Poisoning*' with the claim that increased levels of chlorinated hydrocarbons, chronic exposure to industrial solvents, insecticides or pesticides may resemble an illness resembling CFS - as may silicone breast implants. Further on in the document in Box 2.3 Clinical Practice Guidelines for CFS, 2002, '*Alternative causes of CFS*', occult malignancy is mentioned as occupational and environmental factors e.g. organic solvents heavy metals. There appears to be some inconsistency in the guidelines which supports a relationship between fatigue states arising from MCS/CFS.

References

Winder, C., 1994 ; Bartha, I et al. 1999; Buchwald D and Garrity D. 1994.; Ziem G and McTamney. 1997; Ziem G. 1999; Royal Australian College of Physicians Clinical Practice Guidelines for CFS 2002.

TREATMENT/MANAGEMENT STRATEGIES

Government has a moral and ethical responsibility to protect the public from exposure to hazardous substances that can cause disease and disability. The number one management strategy on a public/government level is a new approach to chemical policy that reduces exposure to potentially harmful chemicals (UK RCEP. 2003).

Better regulation of chemicals is urgently needed as we currently have little data to support the safety of most chemicals we use. The UK Royal Commission on Environmental Pollution in their 24th report (2003) recommended substitution of hazardous substances with those of lower hazard; and where synthetic chemicals are found in biological fluids such as breast milk and human tissue, they should be removed from the market immediately. www.rcep.org.uk. In Europe a new regulatory framework was proposed (REACH). In Australia, NICNAS is currently inviting community views on a new model for regulating industrial chemicals. www.nicnas.gov.au

Any new regulation should take into account public access to information about chemicals in environmental exposures, indoor/outdoor environment and consumer products. Examples are industrial emissions, pesticides in the home or public places, chemicals used in products purchased or to which people are exposed. Currently, some information is regarded as Commercial Business Information with no public right to know. It is not ethical to allow the public to be exposed to harmful chemicals and not give them access to necessary information to deal with any adverse health impacts that arise. Human rights need to be respected. Public access to information needs to be legislated.

Legislative protection for MCS sufferers is essential. Due to the difficulty in finding a chemical free place to live, legislated areas need to be designated. MCS sufferers require stability in order to provide certainty of not being within a development area and built out, or not having an industrial estate, golf course, or farms etc within a range where these could exacerbate MCS. Public housing should be available in regulated MCS areas and financial assistance available for relocation and remote living costs. Buffer zones such as wildlife corridors should protect chemical free areas. This could be a cheaper option than having MCS sufferers living in cities where exposures are unavoidable and health costs to the community are high. Currently, some people cannot find a suitable place to live and live in their cars or in modified caravans. They become nomadic in their search for a safe place to live.

Diagnosis and management early in the course of MCS is the major treatment/management strategy. Other essential components are information about the illness and supportive care. Chemicals that trigger reactions need to be identified so that avoidance management strategies can be put in place to reduce adverse health impacts and worsening levels of ill health. Avoidance early in the course of the illness will also assist to prevent the 'spreading factor' where chemical sensitivity becomes multiple chemical sensitivity.

As with the management of CFS it is essential that a program of reassurance and supportive care is established. Medical practitioners should never trivialise the level of illness and suffering so as not to alienate or distress the MCS sufferer. Education of the MCS sufferer is essential as he/she needs to understand the nature of chemical sensitivity in order to successfully manage the disease. Management plans should be discussed for physical rehabilitation; to evaluate new symptoms or deterioration of function. Supporting the family is also important to reinforce the existence of MCS as a valid disease and the need for the family member with MCS to be nurtured. Medical practitioners may need to act as advocates for patients when required to assist with access to Social Security and disability support services, negotiations with educational institutes and employers. Isolation and inactivity should be discouraged when possible and MCS sufferers should be encouraged to maintain physical, social and intellectual pursuits with employment maintained if possible. Once employment is not possible income disadvantage compounds problems.

Lloyd and Pender estimated the economic impact of CFS in 1992. The study was done by calculating the direct and indirect costs arising from the disorder. Data was obtained by questionnaire from CFS patients regarding usage of health resources, income and employment. In addition Medicare data on the incidence and fees for each Schedule item for these patients was obtained. The conservative cost of CFS in the area surveyed with a prevalence of 37.1 cases per 100,000 was \$396,000. When extrapolated to the Australian population it was estimated that CFS would generate an annual cost of around \$59 million (Lloyd A R and Pender H., 1992).

“Life impact research shows that people with MCS tend to spend a considerable amount of their resources on health care, often pursuing a large number of therapies. Gibson et al. (1996) found that 305 persons with MCS reported spending almost \$6,000, or half of their personal income in the past year, and almost \$35,000 total on medical expenditures since developing MCS. Respondents saw a mean of 8.6 practitioners each, but perceived only a quarter of them to be helpful. Still, patients report having medical needs that remain unmet and experiencing considerable iatrogenic harm (Engel et al. 1996).”

Those with MCS experience a significant loss of lifestyle and functional impairment (Davidoff & Engel, 1996)

Do you consider MCS treatable/manageable?

(Distinguish treatment versus management)

In general the best strategy to use by those most affected is to treat the symptoms and manage the problem. Although avoidance appears to be a simple measure in reality is it very difficult to achieve due to the ubiquitous prevalence of the offending substances. For example it is difficult to avoid irritant fragrance chemicals due to the huge number of products and materials that contain them. These products (eg cleaning products, air fresheners) are used in public buildings including health facilities and this is apart from the fragranced products being worn by staff. This represents just one category of irritant chemicals, when the problem is expanded to other groups of chemicals such as pesticides, solvents, smoke, motor fumes etc avoidance becomes extremely difficult.

Success of any treatment will depend on the level of exposure, chemical(s) involved, nature of the damage done and individual variability. Health can be improved especially if the problem is diagnosed early and further exposures avoided. Avoidance as a strategy is validated in the Worksafe Legislation and many of the cited references in this document. Chemical free living for those severely sensitive is a must.

What do you regard as successful/unsuccessful strategies for treatment/management?

The most successful underlying strategy for all is avoidance of the triggering substance/s. Other options depend on the individual, their age, how early intervention is started, their state of health, access to health treatment and economic circumstances etc. The following table lists a number of successful and unsuccessful strategies.

Successful	Unsuccessful
<p>On a Government Level</p> <ul style="list-style-type: none"> ◆ Better government regulation of chemicals to prevent sensitising or irritant exposures ◆ Legislation of Community Right to Know to allow the public access to necessary information ◆ Better regulation of toxic substances to assistance primary prevention by reducing exposures ◆ Recognition of the illness would lead to a better understanding of individuals with MCS and their needs. (Silberschmidt, M 2005) ◆ Reassurance for MCS sufferers that it is not their fault they are ill and have such problems. Poor government regulation and lack of information and assistance is a contributing factor to their problems. <p>On a personal level</p> <ul style="list-style-type: none"> ◆ Chemical free living ◆ Avoidance of chemicals/allergens ◆ Unpolluted environment, ideally away from urban smog and rural chemicals ◆ Low emission housing and products ◆ Air filtration to reduce chemicals in immediate 	<ul style="list-style-type: none"> ◆ Many medications. These contain phenolic compounds and other substances that can induce reactions in a chemically sensitive individual e.g. colourings, flavourings, other additives, multiple medications in one tablet. ◆ Misdiagnosing the problem ◆ Ignoring the problem ◆ Failure to understand the nature of MCS and the role of environmental pollutants and other factors that trigger reactions. ◆ Not believing that someone has MCS ◆ Psychiatric labelling is unhelpful as some chemicals are neurotoxic substances and can damage the CNS <p>Some treatments rated more likely to harm than help (Gibson PR, 2003)</p> <ul style="list-style-type: none"> ◆ Zoloft ◆ Prozac ◆ Elavil ◆ Other antidepressants ◆ Valium ◆ Antiseizure medications (other than Neurontin) ◆ Xanax

<p>environment</p> <ul style="list-style-type: none"> ◆ Food grown free from chemical inputs - organic/biodynamic ◆ Provocation/neutralisation testing to determine offending substances and foods ◆ Desensitisation may be an option ◆ Detoxification maybe an option if the body burden of lipid soluble chemicals is high. Detox can reduce the intensity of reactions and allow a faster recovery rate ◆ Some nutritional therapies are of assistance especially antioxidant therapy and nutrients that assist with the function of organs e.g liver ◆ Herbal medicine, traditional Chinese medicine and homoeopathy are found by some people to help. They can often improve quality of life, alleviate symptoms or provide a cure that can allow sufferers to regain some normality ◆ Dietary Modification, eg low phenolic content & avoidance of known allergens and additives (food allergy/sensitivity) ◆ Oxygen as required ◆ Physiotherapy ◆ Occupational therapy ◆ Massage therapy, reflexology ◆ Meditation ◆ Joining an MCS support group can assist some people. Support groups are often able to provide information on coping with MCS on a daily basis and assistance with helpful practitioners, products and services www.mja.com.au/public/guides/cfs/cfs2.html ◆ Family support and counselling ◆ A supportive relationship with health care practitioners and services ◆ Psychological and social support 	<ul style="list-style-type: none"> ◆ Microhydrin ◆ Acyclovir (Zovirax) ◆ P-N for chemicals with preservative ◆ Glutathione in nasal spray ◆ UltraClear ◆ Hydrogen peroxide
---	--

Were goals defined for your treatment?

The aim of most treatments is for sufferers to be able to live as normal a life as possible, take part in society and have quality of life. Treatment goals are again dependent on many individual factors such as age, degree of sensitisation and number of chemicals. The earlier the intervention the more positive the prognosis.

Can you identify any factors that have influenced the course of your condition to date?

- ◆ General state of health, other diseases, eg diabetes, obesity, allergy, asthma
- ◆ Age,
- ◆ Worsening environmental pollution,
- ◆ Unavoidable exposure to chemicals that cause adverse health impacts
- ◆ As with any disability or chronic illness the inability to work creates income disadvantage. In the case of MCS there exists a high level of special need and those with resources have a better opportunity to recover than those on pensions or low incomes. Low income groups often cannot afford chemical free food, essential nutrient supplement, medications, chemical free living, medical and allied medical care that they need. Lack of access can lead to a worsening of their condition.
- ◆ Inability to access low emission housing
- ◆ Lack of access to appropriate health care;
- ◆ Inability to find a medical practitioner who understands MCS. Doctors who work in this area are usually in the private system, expensive and unaffordable for those on pensions and low incomes.
- ◆ Lack of access to effective aids - e.g. air filters, effective face masks, oxygen at home;

- ◆ Individuals with severe MCS cannot enter medical facilities for essential or emergency care. Currently, health facilities do not cater for their special needs e.g. ambulances, hospitals, GP surgeries, allied care. Recently an elderly ASEHA member (Valerie) who has emphysema was admitted to hospital as a medical emergency following exposure to fragrance at a GP surgery. The GP surgery did not believe she was sensitive to fragrances and could lose consciousness; instead they became angry with her and refused to give her oxygen when she developed respiratory distress. As her condition deteriorated they called an ambulance. The paramedics arrived wearing fragrances and she was unconscious on arrival at the hospital. Neither the hospital nor the GP surgery believed Valerie that perfume exposure could render her unconscious. The hospital also became angry with her because she constantly complained about fragrance exposure and discharged her untreated. She is elderly, extremely frail and unwell and does not think she will live much longer. It is not unusual for MCS sufferers to be discharged from hospital untreated, or leave a GP surgery without assistance. It is not the first time Valerie has been discharged from hospital untreated. Fragrances are known respiratory irritants.
- ◆ It is not unusual for MCS sufferers to become depressed because they have lost the support of family and friends, live isolated and cannot socialise. The hopelessness of not being able to get any help from the health system or be able to afford tests and treatments not provided on PBS sometimes results in suicide.
- ◆ Resistance by professional medical associations, government etc to recognise MCS and assist sufferers
- ◆ No access to medico-legal support, specialised advocacy services or medical specialists

Do you consider that MCS can be cured/controlled?

(eg able to live in the everyday world, symptom free, return to normal quality of life?)

This is an individual thing dependent on intensity of exposure, chemicals involved, individual susceptibility, age, gender etc. Some people may return to a normal life, others will not. Those with the best chance are those who can afford to and have an adequate level of support to live in a remote area with clean air, organic food and chemical free housing. Some make a good recovery after a lengthy period of time (years). Chemical free living is the cornerstone of treating and living successfully with MCS. Legislated MCS living areas need to be developed to guarantee chemical free living which should allow recovery of those most affected so that they may return to a productive life.

What assistance do you need or have you needed in learning to live with MCS?

Initially the most important things are to be listened to, reassured that you are not alone with the problem, treated with dignity by the medical profession and to find some one with some answers. At the moment this is the role of support groups for MCS who provide information and resources to find medical practitioners, legal representation as well as education for MCS sufferers to assist them to manage their disease as best they can.

The needs of individuals with MCS are complex. Currently, there are no specialists that we know of in Brisbane who understand the health problems and the degree of disability. There are also few service providers who are able to make an accurate assessment of need. Assistance and needs for those with MCS may best be summed up as follows:

Regulatory needs

- The Right to Health. The World Health Organisation defines health as 'a state of complete physical, mental and social wellbeing and not merely the absence of disease, or infirmity. The WHO Bangkok Charter (See Appendix E) identifies health promotion as one of the actions required by the globalised world to address health issues.
- Access to information about chemicals in products (in formulation)
- A reduction in the strength of fragrances. These should not be discernable any more than one meter away from the wearer
- Education of the wider community to accept that some chemicals are harmful and can cause medical emergencies and ongoing exacerbations of already chronic ill health
- Better application of the precautionary principle

Needs associated with personal issues related to chronic illness

- Assistance with coping skills
- Management plan

- Identification of foods, substances and products in the home, work and public environment that can trigger a reaction
- Education to assist MCS sufferers to manage their lives
- Education about MCS for families of MCS sufferers to assist them to support the sufferer
- Relationship/communication skills

Communication/Information needs: These needs are a result of disability in being able to access information and services, or sensitivity to printed materials.

- Telephone for communication, business activity and emergency assistance
- Computer/internet access for communication and business activity.
- Support groups,
- Library,
- TV with recorder/DVD player,
- Radio with audio tape deck and CD player

Health and Allied Care Service needs –

Education about MCS is essential for all medical, emergency service and allied care practitioners/service providers. All providers must be fragrance free, facilities pesticide free and assistance given with respect for the special needs of those with MCS. Examples of health and allied care services required are listed below

- General practitioners,
- Specialist physicians,
- Natural therapists
- Home care,
- Home nursing,
- HACC services - physio, OT, Podiatry etc
- Pain management, including access to physiotherapy when required
- Respite/hostel/nursing home - chemical free,
- Chronic illness/loss/grief counselling,
- Disability support,
- Social workers,
- Rehabilitation,
- Pathology/x-ray/imaging facilities
- Ambulance staff/paramedics

Specialist advocacy needs

- Social workers,
- Politicians,
- Legal profession,
- Support groups
- Specialist advocates to take cases to the Human Rights and Equal Opportunities Commission or State Anti Disability Discrimination Commissions.
- The establishment of an MCS advocate or ombudsman due to the extensive nature of the problem.

Legal/financial assistance

- Medico-legal support,
- Social Security/superannuation/workers compensation/disability payout,
- Childcare,
- Financial support
- Recognition of the need for extra financial support for those with MCS is required due to the nature of the disability and the high level of special need in all facets of living
- Transport/parking concessions.

Meeting special needs

- Access to low emission housing in a low chemical environment, home modifications, air/water filtration, low emission products.
- Relocation costs and assistance to relocate to a more suitable environment e.g. out of urban environment, away from coastal wetlands and constant mosquito spraying, farming pursuits, and a sufficient distance from neighbours not to be affected by the chemicals they use e.g. fragrances, pesticides, disinfectants/detergents, paint or solvent based product

- A smoke free environment
- More resources (financial) for access to organic food that does not increase chemical levels
- Access to appropriate medical and allied care in low or chemical free health care facilities where all health and allied care staff are fragrance free
- Access to therapies that are effective or supportive e.g. Chinese medicine, reflexology, massage, homoeopathy; physiotherapy.
- Access to aids such as oxygen at home, masks, air filters, water filters, sauna at home,
- Access to public transport
- Assistance to maintain car when mobility and MCS disability prevent access to public transport,
- Assistance with the purchase of mobilised wheelchairs,
- Access to chemical free hostel and nursing home accommodation respite/crisis facilities when needed. Currently we have no suitable crisis accommodation for emergency situations e.g. houses nearby being painted, maintenance on our homes.
- Access to distance education,
- MCS awareness counselling for families and partners, grief counselling
- Employment at home. Some sufferers may be able to work at home. If this is possible every support should be given to allow this as income disadvantage adds another tier of hopelessness when there are treatments or courses of action that are helpful but unaffordable.
- Financial assistance with necessary home modifications

Those with MCS who are at the severe end of the disability spectrum may require a more intensive multidisciplinary approach to rehabilitation and other support.

Are there any factors that you consider appear to have influenced the course of your condition?

(eg time, early diagnosis access to management course etc)

NEGATIVE FACTORS

Not being able to access resources, information and obtain help early in the stage of the disease is a major setback. It is demoralising, depressing and allows the condition to worsen

- Not being able to get a diagnosis due to the lack recognition of chemical sensitivity
- While not able to get a diagnosis persisting in environments, such as workplaces, that are adversely affecting health and exacerbating the problem
- Lack of supportive care and reassurance that MCS is an organic illness and not imagined.
- Not given education about MCS and how to manage the problem
- Difficulty finding which chemicals have to be avoided
- Not having adequate information about product/food formulations to practice avoidances - some are hidden sources of chemicals
- Not always able to find information on some chemicals
- No legislated right to information
- No high profile preventive programs to flag the issue of chemicals causing harm to human health
- The application of the precautionary principle needs to be improved
- Long delays in obtaining effective manage and treatment from either sympathetic medical physicians or other allied health modalities
- Financial difficulties arising from sensitivities such as loss of job, fees from medial specialists and legal profession, higher costs of organic foods etc
- Facing numerous medical specialists, some of whom are hostile, during the course of worker's compensation claims or other litigation processes, or just trying to find someone who can help.
- Difficulties in finding a 'safe location' to live in order to begin getting better. In my case S.M., over the last 12 years I and my partner have been progressively moving further away from large cities (Brisbane), to a coastal suburb (Redcliffe), to a small rural village (< 400 people), to a 100 acre property 8 km from an even smaller village in country that is not conducive to high intensity farming. Even here it is close to a clean environment but not 100%. And I am one of the lucky ones who have had the support and ability to make these moves.
- MCS sufferers are often subject to discrimination and human rights abuses
- Inability to access care/services in a 'safe' environment in spite of statements that we are entitled to high quality, safe, appropriate care delivered in an environment in which you feel safe. (Qld Health. Leaflet.)

POSITIVE FACTORS

These positive factors allow an individual to manage their problem as best they can.

- Getting a diagnosis
- Identifying chemicals that need to be avoided
- Assistance with management/avoidance
- Education and assistance to deal with reactions as they occur or when they are unavoidable
- Assistance with dietary modification when food allergy and phenolic sensitivity exists
- Management of diseases outside of MCS. For example management of co – morbid conditions such as asthma, skin allergies
- Access to nutritional and alternative therapies that are effective as current medical science has little to offer
- Overall reduction in environmental exposures

RESEARCH AND EDUCATION

Are you aware of research currently being undertaken to improve the knowledge and understanding of MCS?

Research on MCS, general chemical hypersensitivity & allergy, body burden of chemicals and the impact of the many chemicals in our environment on the health of the population is being done by many researchers and Institutes some of which are listed below. MCS research has been progressing knowledge on models/mechanisms of the syndrome, diagnostic tests, criteria for MCS diagnosis and treatment and management strategies (see reference list). There are many studies into the health effects of common chemicals on children, the ASEHA website Children's Health Page provides more information and references (www.asehaqld.org.au)

As well as the numerous references we have cited so far, the following websites contain some very useful information.

- Nova Scotia Environmental Health Centre www.cdha.nshealth.ca/facilities/nsehc/index.html The objectives of the Nova Scotia Centre are to provide validated testing and treatment for environmental sensitivities; patient education; disseminate knowledge through publications, conferences and newsletters; research environmental sensitivities in close collaboration with affected individuals, health care professionals and research scientists; advise provincial and national agencies working to develop policies related to recognizing, preventing and treating environmental sensitivities.
- US NIEHS www.niehs.gov - studying the impact of chemicals on the human body and environment. Developing gold standard tests for identifying chemical injury
- Environmental Health Perspectives - Journal of NIEHS where latest research is published. Available online at www.ehp.niehs.nih.gov
- US CDC- www.cdc.gov monitoring humans for body burden of chemicals or damage done by chemical exposure Reports online www.cdc.gov/exposurereport.htm
- US ATSDR - database and information source www.atsdr.gov
- US EPA - www.epa.gov
- US EPA Toxicity and Exposure Assessment for Children's Health (TEACH) <http://www.epa.gov/teach/>

Overseas and Australian Government are responding to the growing evidence of the existence of chemical sensitivity by commissioning their own reports and surveys to determine the extent of the problem within their own countries.

Overseas and Australian Reviews and Reports into MCS

Parliament of South Australia. Social Development Committee. 2005. Inquiry into MCS	The Social Development Committee of the South Australian Parliament inquired into MCS and handed down their findings on 5 July 2005 with eleven recommendations.
NSW Health. The 2002 NSW Health Survey included a question on chemical sensitivity in order to determine the prevalence of MCS in Australia. It was acknowledged that on the basis of overseas studies with estimates of 26% of adults diagnosed with MCS, that the burden of MCS illness in Australia may be substantial.	Using a set of six consensus diagnostic criteria which defined MCS, the NSW Adult Health Survey included questions on chemical sensitivity. Respondents were asked Do certain chemical odours and smells regularly make you unwell? And Have you ever been diagnosed with a chemical sensitivity? New South Wales Health Survey Program. 2002. New South Wales Adult Health Survey. www.mhcs.health.nsw.gov.au
NZ Government MCS Report NZ Environmental Risk Management Authority (Read, D. 2002.) The report recommends legislative and regulatory changes to protect the chemically sensitive in the community.	New Zealand review of MCS. This review identified pesticides and solvents as chemicals that most frequently cause symptoms in individuals with MCS.
The Danish Government Environmental Board has published a report on MCS based on literature, meetings, workshops and reviews. (Silberschmidt, M 2005). The Cullen criteria was	The report lists conferences, workshops and reports in Chapter 3, pp.29 - 38 In Denmark MCS is called odour and chemical sensitivity. (Silberschmidt, M. 2005. Multiple

<p>used to distinguish MCS from other environmental disease. The report identifies pesticides, fragrances and solvents as major sources of MCS and highlights the individual susceptibility of some in the community. The similarity between MCS and CFS/FM syndrome was acknowledged. Prevention was regarded as the best form of protection for MCS sufferers and avoidance of chemicals was the main recommendation.</p>	<p>Chemical Sensitivity, MCS. Danish Ministry of the Environment, Environment Protection Agency. www.miljoestyrelsen.dk</p>
<p>UK Review. This review of MCS commissioned by the Institute of Occupational Medicine in Scotland indicated that although data was patchy and there were data gaps, there is evidence to support that MCS does exist.</p>	<p>Graveling R A, Pilkington A, George JPK, Butler MP, Tannahill SN. 1999. A review of MCS.</p>

What do you consider to be the gaps in knowledge associated with identifying and treating people who suffer from MCS

Clinical Practice and scientific investigations:

- ◆ A lack of agreement on a validated symptom profile characteristic of MCS is contributing to a lack of diagnostic procedures and inhibits clinical practice and scientific investigations (Lacour, 2005). The work by Lacoura et al., 2005, is beginning to untangle the complexity of numerous symptoms into a comprehensive differential diagnostic procedure.
- ◆ Aaron and Buchwald, 2001, commented that there is inadequate information available on the cause, pathophysiology, natural history & prognosis, and medical management of syndromes
- ◆ such as MCS, CFS, and Fibromyalgia for differential diagnosis of these 'unexplained clinical conditions'.
- ◆ To date doctors and regulators have refused to accept the existence of MCS in spite of it being noted in the occupational health literature for the last fifty years (Hileman, 1991)
- ◆ Unknown toxicology of mixtures of chemicals and their impacts on human health
- ◆ Data gaps exist for most chemicals in common use (UK RCEP, 2003) Better regulation is essential for primary prevention. (UK RCEP, 2003; EU REACH, 2003 europa.eu.int/comm/environment/chemicals/chemicals/reach.htm).
- ◆ Little attention has been paid to the extent to which to which chemical sensitivity coexists with other medical or psychiatric conditions. Manifestations of MCS are diagnosed (e.g. migraine, asthma, allergic rhinitis, hay fever) but the underlying cause not recognised.
- ◆ The cost to the community in disability, health and allied care provision to those with MCS
- ◆ Developmental problems associated with infants exposed to chemicals in utero e.g. neurotoxins or endocrine disruptors. These children can be born with deformities, developmental delay and other diseases that can progress into cancer or other chronic conditions later in life. Such an individual can live a life of chronic ill health resulting in loss of human resources to the community as well as economic loss. Chemical sensitisation is a problem of huge proportions for public health.

Other gaps/obstacles include

- ◆ The scale of the problem due to limitations of data and methodology
- ◆ Problems finding an unexposed control group, due to the ubiquitous nature of common chemicals
- ◆ The effects of multiple exposures of varying doses and durations
- ◆ Special risks for children, pregnant women and other potentially susceptible people
- ◆ The long term effects of chronic exposures to low levels of chemicals is currently unknown
- ◆ General lack of knowledge of the impacts of chemicals on human health and the environment. Recent correspondence from NICNAS in regard to its Existing Chemicals Program Review notes there are some 38,000 existing chemicals in Australia and most have not been assessed for health, safety and environmental risk. Analysis by the European Union (who acknowledges 100,000 chemicals) estimates that around 75% of all industrial chemicals traded globally lack adequate health, safety and/or environmental information. www.nicnas.gov.au We have a need to know which chemicals are sensitising agents or cause other harm to our health.

Within Australia

- ◆ Denial of government that there is a problem following exposure to some substances
- ◆ No acceptable diagnostic criteria or treatment in the mainstream medical profession
- ◆ Not enough awareness of MCS in the community

- ◆ Inadequate consultation by government, regulators and medical training courses etc with groups who support MCS sufferers and who therefore know what the issues are. Hopefully this project is a turning point.

Are you aware of any action being taken to overcome the education and knowledge gaps regarding MCS?

Although scientific investigations are being done to advance knowledge of many aspects of MCS and chemical hypersensitivity, little seems to be filtering down to mainstream medicine physicians who deal with the public and are one of the main sources of education for the general public on health issues.

References for clinical practice and scientific investigations to overcome knowledge gaps have been listed throughout this document. Overseas and Australian Government actions include those listed in the first question of this section – “*Are you aware of research currently being undertaken to improve the knowledge and understanding of MCS?*”

At a community level, education of the general public has only been through support groups who endeavour to improve education and resources for themselves and the wider community. Some examples of measures that have been undertaken are:

- Information leaflets and newsletters
- Websites such as ASEHA www.asehaqlld.org.au, www.rohan.sdsu.edu/staff/lhamilto/mcs/index2.html#articles and MCS Referrals and Resources www.mcsrr.org/ with educational material and links to useful information
- ASEHA occasionally has medical students on placement to endeavour to get education about MCS into the medical course.
- ASEHA is also encouraging the Royal Brisbane Hospital to finalise its MCS Policy so that individuals with MCS can access the hospital for medical treatment. Currently MCS sufferers are very disadvantaged in health and allied care.
- ASEHA encourages individuals with discrimination and human rights issues to take their cases before the Human Rights and Equal Opportunities Commission or State Anti Discrimination Commissions.
- ASEHA is engaged in systems advocacy for those with MCS

Can you suggest any strategies that might improve or overcome gaps in education and knowledge about MCS or assist in enabling people who suffer from this condition to be more effectively supported and understood?

Specific to MCS individuals

- Recognition of MCS at all tiers of government and in health care, disability and social services and the development of evidence based, Government Policy on MCS at State and Federal level to ensure consistency and best practice standards
- Consult with people who are sufferers and groups that support them - ask them - fund research. Many MCS sufferers are not in the medical system as it has little to offer them. In order to gather data on MCS to develop medical protocols, programs and services etc, MCS sufferers need to be encouraged back into the medical system. Extensive consultations with MCS groups and sufferers would need to be done to achieve this as most of us have lost faith in the medical system.
- Fund the support groups to a high level so that they can better support members with services such as social workers, nurse practitioners to deal with emergencies for those who live alone and cannot access medical services, physiotherapists, occupational therapists, supported accommodation; nursing homes that will accommodate the need for chemical free accommodations and food. The emergence of a support group for a specific medical problem or disability is usually flagging an area of unmet need and research. There may be many organisations that support members with diseases that are chemically related e.g. neuromuscular disease, migraine, asthma, spina bifida
- Provide MCS sufferers with access to medical aids that will reduce their exposures and improve quality of life
- Provide low emission housing in clean air for those on low or moderate incomes
- Improve income base so that MCS sufferers can access chemical free food, nutritional supplements, alternative health care e.g. TCM, herbal medicine, homoeopathy, naturopathy

- Establish an environmental health center in Australia so that those with MCS can access care in a suitable environment. This center should produce research data that will assist in the understanding and treatment of MCS for future generations
- Implement guidelines in all hospitals for admitting, accommodating and treating individuals with MCS
- Indicators need to be established to identify unrecognised disease/disability such as MCS so they can be included in service provision and planning for future health and disability service provision. Diseases such as MCS have both health need and disability need and there appears to be no process to identify and monitor these so that they become established in medical and disability services.

Research Programs

- Encourage Australian research on chemical sensitivity and gather data on the prevalence and epidemiology of MCS in Australia
- Educate the medical profession – introduce MCS diagnosis, treatment and management in the medical course curriculum and the Continuing Medical Education (CME) program to upgrade currently practising physicians.
- Assist and encourage those medical professionals in Australia that are acknowledging MCS and treating individuals with the condition
- Identification of the major sensitising agents that initiate and trigger MCS.
- Develop diagnostic criteria for the medical profession eg clinical diagnosis; diagnosis by exclusion. In NZ 'poisoning arising from chemical contamination of the environment' is a notifiable disease. However, notifications are rare due to the lack of acceptable diagnostic criteria and are thought to be underreported (Dean, 2002).
- Gather reports of adverse health incidences following the use of products/exposures.
- Initiate programs such as US Centers for Disease Control NHEXAS (exposure to chemicals) and monitor Australians for their body burden of toxic chemicals.

Public health programs

- Better regulation of chemicals that are known irritants to restrict peoples exposure to them
- Remove barriers to access of information - legislate consumers' right to know what chemicals are in the products they purchase or to which they are exposed.
- Reduce chemical exposure in the public domain
- Encourage development and use of low emission products in public facilities especially health services
- Develop fragrance and pesticide policies in health care facilities and public buildings and on public transport so that MCS sufferers have access to them. Such a policy is also beneficial to workplace productivity as fragrances affect the health of many with allergy and respiratory disease and can result in lost work days. Fragrances are a health hazard.
- Regulate the chemicals used in fragrances that are fixatives and strengthen the aroma. Fragrances should degrade in a short space of time and the fragrance only detectable one meter away from the wearer.
- Print and electronic media promotion of MCS as per other health campaigns e.g. quit, sun cancer
- Printed material about MCS needs to be developed and published by health and other government departments. This information needs to be available in public places
- Educational materials on the dangers of chemicals and MCS needs to be developed for schools

Social costs of chemicals

Many people with MCS are professional people and have had a productive working life e.g. scientists, nurses. These individuals are now unable to work and take part in the community. As such they represent a significant loss of human resources in the community. In some cases they are now dependent on the public health system, disability services, welfare services and government income support.

ASEHA RECOMMENDATIONS

1. A commitment by Federal Health for an adequate level of funding to establish an ongoing program of research into MCS, that includes:

- Monitoring MCS prevalence,
- Analyzing the social problems that MCS causes and
- The cost to the community of MCS and diseases associated with chemical exposures
- To assist with the research programs MCS should be declared a notifiable disease in Australia

2. The establishment of a reference group to oversee the research program. Membership should include representatives of relevant government departments and agencies, professional bodies, community organisations that deal with MCS and MCS sufferers. Consumers should always be in equal numbers to bureaucrats and professional representatives.

3. The establishment of an Environmental Health Centre (EHC) to assist with research into MCS and the development of appropriate programs and services. The EHC provides opportunity for ongoing study.

4. The establishment of a case definition for MCS

5. The establishment of a history (health and exposure) taking protocol for MCS with special attention to the uncovering and documenting of exposures to:

- Known sensitizers, neurotoxic agents and endocrine disruptors
- Substances associated with the onset of chemical sensitivity e.g. solvents, pesticides, new or renovated buildings, anesthetics, wood preservatives
- Stressful or traumatic life events
- Protocols for follow up in terms of changes in signs, symptoms & disease over appropriate time periods.
- History taking protocol should include an occupational and environmental exposure history. Outcomes (signs, symptoms and disease) of exposures should be tracked over a sufficiently long period of time to allow for differential diagnosis of MCS.

6. MCS should be included in the medical course curriculum and Continuing Medical Education (CME) process to ensure that all physicians are educated in how diagnose and manage MCS sufferers.

7. Consultation with relevant bodies, professional organisations, community groups and sufferers is required to produce appropriate information sheets on MCS.

8. Investigate current guidelines for chemical usage to establish a public health policy on chemical management. The aim of the policy should be to use less harmful chemicals in order to minimise adverse health impacts on individuals who suffer from allergy, asthma other respiratory disorders and those who are sensitive to chemicals.

9. Ensure that the regulatory structure for chemicals addresses the issues of those in at risk groups in the community, in particular pregnant women, children, those with allergy, respiratory disease and MCS sufferers. Adolescents in the workplace also require special protection from some exposures.

10. There are many issues experienced by MCS sufferers in relation to public facilities and community services. Consultation and collaboration with appropriate health, disability, welfare agencies, MCS organisations and sufferers is needed to establish the level of need of MCS sufferers and implement practical measures to address the issue of disability access.

11. The right to health is paramount. Living areas need to be established for MCS sufferers. These essentially need to be acreages that are protected by legislation against the establishment of industrial estates, golf courses, housing estates, farming or other pursuits that will pollute the air shed of the MCS living area. Large chemical free buffer zones may need to surround the area. These areas need to have clean air, clean soil and clean water to begin with. Some assistance to establish settlements including costs of remote living is essential. Severe cases need to live chemical free until recovery is achieved.

12. A working group urgently needs to be convened to develop MCS hospital guidelines to provide access to health care for even the most severely sensitive individuals. These guidelines need to be

applied to ALL Australian hospitals. At least 30% of the representation on this committee should be composed of MCS support groups and/or sufferers.

13. Public education about the hazards of chemical exposure and the health problems that can arise is urgently needed. Educational material should be aimed at encouraging individuals to reduce their usage of chemicals in favor of less toxic options and to recognise adverse reactions as they occur.

14. As a priority, an investigation needs to be held into the toxicity of fragrances and problems associated with fragrance exposure in the community. Fragrances are mixtures of chemicals, mostly solvents. They contain known human allergens, sensitising agents, carcinogens, neurotoxins, endocrine disruptors. Urgent legislation is essential to ensure that the strength of the odours/fumes and the life of the fragrance is reduced. Fragrances should not be discernable any more than one meter away from the wearer or point of application e.g. detergents, disinfectants, laundry products etc and should degrade in a short space of time.

15. Legislation is essential to ensure that those with MCS have prior notification of any pesticide application in their environment e.g. neighbours treating for pest control, local council pest/weed programs.

16. Some effort needs to be made to research the full range of diseases that are triggered or caused by chemical exposures, and the cost of these to the community in terms of health, allied care and other welfare services. Only in this context can we understand the full impact of chemical disease. Some individuals will be born already damaged by chemical exposure and will experience cradle to grave disability and ill health. (Massey and Ackerman. 2003)

References:

- Amdur, M O et al. 1991 Casarett and Doull's Toxicology: the basic science of poisons. Fourth ed. Pergamon, NY. p.15
- Ashford, N.A. and C.S. Miller. 1991. Chemical Exposures: Low Levels and High Stakes, 1st edition. Van Nostrand Reinhold, New York.
- Ashford, N and Miller, C. 1992. Case definitions for Multiple Chemical Sensitivity. In Multiple Chemical Sensitivities: A Workshop. National Academy Press. Washington, DC. pp.41-45
- Ashford, N.A. and C.S. Miller. 1992. Case Definitions for Multiple Chemical Sensitivity. In Multiple Chemical Sensitivities: Addendum to Biologic Markers in Immunotoxicology. Anonymous National Academy Press, Washington, D.C. 41-63.
- Ashford, N.A. and C.S. Miller. 1993. Multitple chemical sensitivity. Health Env.Digest 6:11
- Ashford, N.A. and C.S. Miller. 1998. Chemical Exposures: Low Levels and High Stakes, 2nd edition. Wiley & Sons, New York.
- Ashford, N.A. 1999. Low-level chemical sensitivity: implications for research and social policy. Toxicol Ind Health 15:421-427.
- Ashford NA. 2004 Implementing the Precautionary Principle: incorporating science, technology, fairness, and accountability in environmental, health, and safety decisions. International Journal of Occupational Medicine & Environmental Health. 17(1):59-67.
- Bartha, Liliane. 1999. Multiple Chemical Sensitivity: A 1999 consensus. *Archives of Environmental Health*. 54(3): May/June pp.147-149
- Baldwin CM. Bell IR. O'Rourke MK. 1999 Odor sensitivity and respiratory complaint profiles in a community-based sample with asthma, hay fever, and chemical odor intolerance. *Toxicology & Industrial Health*. 15(3-4):403-9.
- Baldwin CM. Bell IR. Guerra S. Quan SF. 2004. Associations between chemical odor intolerance and sleep disturbances in community-living adults. *Sleep Medicine*. 5(1):53-9.
- Bell, I.R. 1975. A kindling model of mediation for food and chemical sensitivities: biobehavioral implications. *Ann.Allergy* 35:206-215.
- Bell, I.R. 1982. *Clinical Ecology*. Common Knowledge Press, Bolinas, CA.
- Bell, I.R. 1987. Environmental illness and health: the controversy and challenge of clinical ecology for mind-body health. *Advances* 4:45-55.
- Bell, I.R., C.S. Miller, and G.E. Schwartz. 1992. An olfactory-limbic model of multiple chemical sensitivity syndrome: possible relationships to kindling and affective spectrum disorders. *Biol.Psychiatry* 32:218-242.
- Bell, I.R., G.E. Schwartz, J.M. Peterson, and D. Amend. 1993. Symptom and personality profiles of young adults from a college student population with self-reported illness from foods and chemicals. *J.Am.Coll.Nutr.* 12:693-702.
- Bell IR, Schwartz GE, Peterson JM, Amend D. 1993 Self-reported illness from chemical odors in young adults without clinical syndromes or occupational exposures. *Arch Environ Health*.;48:6-13.
- Bell, I.R., G.E. Schwartz, J.M. Peterson, D. Amend, and W.A. Stini. 1993. Possible time-dependent sensitization to xenobiotics: self- reported illness from chemical odors, foods, and opiate drugs in an older adult population. *Arch.Environ.Health* 48:315-327.
- Bell, I.R., G.E. Schwartz, J.M. Peterson, and D. Amend. 1993. Self-reported illness from chemical odors in young adults without clinical syndromes or occupational exposures. *Arch.Environ.Health* 48:6-13.

Bell, I.R., E.J. Markley, D.S. King, S. Asher, D. Marby, H. Kayne, M. Greenwald, D.A. Ogar, and S. Margen. 1993. Polysymptomatic syndromes and autonomic reactivity to nonfood stressors in individuals with self-reported adverse food reactions. *J.Am.Coll.Nutr.* 12:227-238.

Bell, I.R. 1994. White paper: Neuropsychiatric aspects of sensitivity to low-level chemicals: a neural sensitization model. *Toxicol.Ind.Health* 10:277-312.

Bell, I.R., G.E. Schwartz, D. Amend, J.M. Peterson, and W.A. Stini. 1994. Sensitization to early life stress and response to chemical odors in older adults. *Biol.Psychiatry* 35:857-863.

Bell, I.R., J.M. Peterson, and G.E. Schwartz. 1995. Medical histories and psychological profiles of middle-aged women with and without self-reported illness from environmental chemicals. *J Clin Psychiatry* 56:151-160.

Bell, I.R., J.M. Peterson, and G.E. Schwartz. 1995. Medical histories and psychological profiles of middle-aged women with and without self-reported illness from environmental chemicals. *J Clin Psychiatry* 56:151-160.

Bell, I.R., J.K. Wyatt, R.R. Bootzin, and G.E. Schwartz. 1995. Slowed reaction time performance on a divided attention task in elderly with environmental chemical odor intolerance. *Int.J Neurosci.* 84:127-134.

Bell, I.R., E.E. Hardin, C.M. Baldwin, and G.E. Schwartz. 1995. Increased limbic system symptomatology and sensitizability of young adults with chemical and noise sensitivities. *Environ Res* 70:84-97.

Bell, I. R., Glowa, J., Sheridan, J., Hudnell, Hk, MacPhail, Rc, Miller, D, Tilson, H, Benignus, V, Boyes, W, Bushnell, P, and Gilbert, M. Workshop on Animal Models of Nervous System Susceptibility to Indoor Air Contaminants, Summary Report, October 19-21, 1994. 1-61. 1995. Chapel Hill, NC, National Health and Environmental Effects Research Laboratory and the U.S. Environmental Protection Agency.

Bell, I.R., R.R. Bootzin, T.P. Davis, V. Hau, C. Ritenbaugh, K.A. Johnson, and G.E. Schwartz. 1996. Time-dependent sensitization of plasma beta-endorphin in community elderly with self-reported environmental chemical odor intolerance. *Biol Psychiatry* 40:134-143.

Bell, I.R., R.R. Bootzin, C. Ritenbaugh, J.K. Wyatt, G. DeGiovanni, T. Kulinovich, J.L. Anthony, T.F. Kuo, S.P. Rider, J.M. Peterson, G.E. Schwartz, and K.A. Johnson. 1996. A polysomnographic study of sleep disturbance in community elderly with self-reported environmental chemical odor intolerance. *Biol Psychiatry* 40:123-133.

Bell, I.R. 1996. Clinically relevant EEG studies and psychophysiological findings: possible neural mechanisms for multiple chemical sensitivity. [Review]. *Toxicology* 111(1-3):101-117.

Bell, I.R., G.E. Schwartz, C.M. Baldwin, and E.E. Hardin. 1996. Neural sensitization and physiological markers in multiple chemical sensitivity. *Regul Toxicol Pharmacol* 24:Pt 2):S39-47

Bell, I.R., C.S. Miller, G.E. Schwartz, J.M. Peterson, and D. Amend. 1996. Neuropsychiatric and somatic characteristics of young adults with and without self-reported chemical odor intolerance and chemical sensitivity. *Arch Environ.Health* 51:9-21.

Bell, I.R., M.E. Walsh, A. Goss, J. Gersmeyer, G.E. Schwartz, and P. Kanof. 1997. Cognitive dysfunction and disability in geriatric veterans with self reported intolerance to environmental chemicals. *J.Chronic Fatigue Syn.* 3:15-42.

Bell, I.R., G.E. Schwartz, R.R. Bootzin, and J.K. Wyatt. 1997. Time-dependent sensitization of heart rate and blood pressure over multiple laboratory sessions in elderly individuals with chemical odor intolerance. *Arch Environ Health* 52:6-17.

Bell, I.R., J.P. Kline, G.E. Schwartz, and J.M. Peterson. 1998. Quantitative EEG patterns during nose versus mouth inhalation of filtered room air in young adults with and without self-reported chemical intolerance. *Int J Psychophysiol* 58:50-57.

- Bell, I.R., G.E. Schwartz, C.M. Baldwin, E.E. Hardin, and J.P. Kline. 1998. Differential resting quantitative electroencephalographic alpha patterns in women with environmental chemical intolerance, depressives, and normals. *Biol Psychiatry* 43:376-388.
- Bell, I.R., C.M. Baldwin, and G.E. Schwartz. 1998. Illness from low levels of environmental chemicals: relevance to chronic fatigue syndrome and fibromyalgia. *Am J Med* 105:74S-82S.
- Bell, I.R., R. Patarca, C.M. Baldwin, N.G. Klimas, G.E. Schwartz, and E.E. Hardin. 1998. Serum neopterin and somatization in women with chemical intolerance, depressives, and normals. *Neuropsychobiology* 38:13-18.
- Bell, I.R., L. Warg-Damiani, C.M. Baldwin, M.E. Walsh, and G.E. Schwartz. 1998. Self-reported chemical sensitivity and wartime chemical exposures in Gulf War veterans with and without decreased global health ratings. *Mil.Med* 163:725-732.
- Bell IR. Baldwin CM. Fernandez M. Schwartz GE. 1999. Neural sensitization model for multiple chemical sensitivity: overview of theory and empirical evidence. *Toxicology & Industrial Health*. 15(3-4):295-304.
- Bell IR. Szarek MJ. Dicenso DR. Baldwin CM. Schwartz GE. Bootzin RR. 1999. Patterns of waking EEG spectral power in chemically intolerant individuals during repeated chemical exposures. *International Journal of Neuroscience*. 97(1-2):41-59.
- Bell IR. Baldwin CM. Schwartz GE. 2001. Sensitization studies in chemically intolerant individuals: implications for individual difference research. *Annals of the New York Academy of Sciences*. 933:38-47.
- Bell IR. Baldwin CM. Stoltz E. Walsh BT. Schwartz GE. 2001. EEG beta 1 oscillation and sucrose sensitization in fibromyalgia with chemical intolerance. *International Journal of Neuroscience*. 108(1-2):31-42,.
- Bowes, D M. 1997. Chemical Sensitivity: Is there a problem? Paper presented to Health & Safety Assessment of Agrichemicals Conference. National Research Centre for Environmental Toxicology 20 - 21 February, 1997. Brisbane, Qld
- Buchwald D and Garrity D. 1994. Comparison Of Patients With Chronic Fatigue Syndrome, Fibromyalgia And Multiple Chemical Sensitivities. *Arch Intern Med* 154:2049-2053
- Caress, S.M. and Steinemann, A.C. 2005. National Prevalence of Asthma and Chemical Hypersensitivity: An Examination of Potential Overlap., *J Occup Environ Med.*;47:518–522
- Caress, S.M., and Steinemann, A.C. 2003. A Review of a Two-Phase Population Study of Multiple Chemical Sensitivities. *Environ Health Perspect* 111:1490–1497. doi:10.1289/ehp.5940 available via <http://dx.doi.org/>
- Caress SM, Steinemann AC. 2004 The prevalence of multiple chemical sensitivities in a population based study. *Am J Public Health.*;94:746 –747.
- Carpenter D O et al. 2002. Understanding the human health effects of chemical mixtures. *Environ Health Perspect* 110(suppl 1):25–42 (2002). <http://ehpnet1.niehs.nih.gov/docs/2002/suppl-1/25-42carpenter/abstract.html>
- Chemical Injury Information Network, www.ciin.org.
- Chenseng, L et al. 2006. Organic diets significantly lower children's dietary exposure to organophosphorous pesticides. *Environmental Health Perspectives* 114(2): 260 - 263
- Cullen, Mark R. 1987. The Worker with multiple chemical sensitivities: an overview. *Occupational Medicine: State of the Art Reviews*. 2 (4): October/December. pp.655-661.

Davidoff AL and Keyl PL. 1996. Symptoms and health status in individuals with Multiple Chemical Sensitivities Syndrome from four reported sensitizing exposures and a general population comparison group. *Archives of Environmental Health*; Vol 51(3); 201-213.

Dermatology website www.dermnetz.org

Deutschen Institut für Medizinische Dokumentation und Information (DIMDI), Internationale statistische Klassifikation der Krankheiten und verwandter Gesundheitsprobleme, 10 Revision, 2000. [International Statistical Classification of Diseases and Related Health Problems, ICD-10-SGB-V, published in November, 2000, by the German Institute of Medical Documentation and Information, DIMDI, by order of the Federal Ministry for Health.]

Elberling J, Linneberg, A., Mosbech, H., Dirksen, A., Menne, T., Nielsen, N.H., Madsen, F. Frølund, L., Duus Johansen, J. 2005a Airborne chemicals cause respiratory symptoms in individuals with contact allergy. *Contact Dermatitis*: 52: 65–72

Elberling, J., Linneberg, A., Dirksen, A., Johansen*, J.D., Frølund, L., Madsen, F., Nielsen, N.H. and Mosbech, H. 2005b. Mucosal symptoms elicited by fragrance products in a population-based sample in relation to atopy and bronchial hyper-reactivity *Clin Exp Allergy*; 35:75–81

Engel LR, Gibson PR, Adler ME, Rice VM. 1996. Unmet medical needs in persons with self-reported multiple chemical sensitivity. Presented at the Annual Meeting of the Southeastern Psychological Association, 20-23 March, Norfolk, VA.

Environmental Health Perspectives <http://ehp.niehs.nih.gov/>

FISHER, B. 1998. Scents and Sensitivity. *Environmental Health Perspectives* 106(12): December ppA594-598

Furlong, C. E. (2000) PON1 status and neurologic symptom complexes in Gulf War veterans. *Genome Res.* 10, 153–155

Gibson PR, Cheavens J, Warren ML. 1996. Multiple chemical sensitivity/environmental illness and life disruption, *Women Ther* 19:63-79.

Gibson, P R et al. 2003. Perceived treatment efficacy for conventional and alternative therapies reported by persons with multiple chemical sensitivity. *Environmental Health Perspectives* 111(12):1498-1504 S

Graveling R A, Pilkington A, George JPK, Butler MP, Tannahill SN. 1999. A review of MCS. *Occupational and Environmental Medicine.* 56(2): 73-85

Haley, R. W., Billecke, S., and La Du, B. N. (1999) Association of low PON1 type Q (type A) arylesterase activity with neurologic symptom complexes in Gulf War veterans. *Toxicol. Appl. Pharmacol.* 157, 227–233

Hilleman, Bette. 1991. Multiple Chemical Sensitivity. *Chemical & Engineering News.* 69(29); 26 - 41. *Special Report.*

Hoover, DR, Donnay A, Mitchell CS, Ziem G, Rose NR, Sabath DE, Yurkow EJ, Nakamura R. 2003. Reproducibility of Immunological Tests Used To Assess Multiple Chemical Sensitivity Syndrome *Clinical And Diagnostic Laboratory Immunology*, p. 1029–1036

Hausteiner C, Bornschein S, Hansen J, Zilker T, Forstl H. 2005. Self-reported chemical sensitivity in Germany: A population-based survey. *Int. J. Hyg. Environ.-Health.* 208; 271-278

International Labour Organisation. *Encyclopaedia of Occupational Health & Safety*, 3rd Ed. Digestive System. www.ilo.org/encyclopaedia/

International Program on Chemical Safety www.inchem.org

- Joffres, M R et al. 2001. Environmental Sensitivities: Prevalence of Major Symptoms in a Referral Center: The Nova Scotia Environmental Sensitivities Research Center Study. *Environmental Health Perspectives*. 109(2): 161-165
- Klaasen et al. 1995. *Casarett & Doull's Toxicology: The basic science of poisons*. Fifth ed. McGraw Hill, NY
- Kreutzer R, Neutra RR, Lashuay N. 1999 Prevalence of people reporting sensitivities to chemicals in a population-based survey. *Am J Epidemiol.*;150:1–12.
- Lacoura,Thomas Zunderb,Klaus Schmidtkec,Peter Vaithd,Carl Scheidta, (2005) Multiple Chemical Sensitivity Syndrome (MCS) – suggestions for an extension of the US MCS-case definition Michael *Int. J. Hyg. Environ.-Health* 208 141–151
- Lloyd A R and Pender H. 1992. The economic impact of chronic fatigue syndrome. *The Medical Journal of Australia*. 157(2):599-601.
- Loblay, R and Swain, A. 1986. Food Intolerance. In *Recent Advances in Clinical Nutrition* 2:169-177.
- Marshall, L., Weir, E., Abelsohn, A., Sanborn, M.D. 2002. Identifying and managing adverse environmental health effects: 1. Taking an exposure history. *CMAJ*; 166(8):1049-55
- Massey R and Ackerman F. 2003. The Cost of Preventable Childhood Illness: The Price WePay for Pollution. *Global Development and Environment Institute Working Paper No. 03-09* www.ase.tufts.edu/gdae
- McKeown-Eyssen, G., Baines, C., Cole, D.E.C., Riley, N., Tyndale, R.F., Marshall, L., and Jazmaji, V. 2004. Case-control study of genotypes in multiple chemical sensitivity: CYP2D6, NAT1, NAT2,PON1, PON2 and MTHFR *International Journal of Epidemiology*; 33:1–8 DOI: 10.1093/ije/dyh251
- MCS Referrals and Resources www.mcsrr.org.
- Meggs, W.J. 1992. Immunological Mechanisms of Disease and the Multiple Chemical Sensitivity Syndrome. In *Multiple Chemical Sensitivities: Addendum to Biological Markers in Immunotoxicology*. Anonymous National Academy Press, Washington, D.C. 155-169.
- Meggs, W.J. 1992. Multiple chemical sensitivities and the immune system. *Toxicol.Ind.Health* 8:203-214.
- Meggs, W. J., Larkin, E. L., and Cleveland, C. H., 1992 Multiple chemical sensitivity may be reactive airways dysfunction. *Internal Medicine News & Cardiology News* , 26..
- Meggs, W.J. 1992. Health effects of indoor air pollution. *N.C.Med.J.* 53:354-358.
- Meggs, W.J. 1993. Neurogenic inflammation and sensitivity to environmental chemicals. *Environ Health Perspect* 101:234-238.
- Meggs, W.J. and C.H. Cleveland, Jr. 1993. Rhinolaryngoscopic examination of patients with the multiple chemical sensitivity syndrome *Arch.Environ.Health* 48:14-18.
- Meggs, W.J. 1994. RADS and RUDS--the toxic induction of asthma and rhinitis. *J Toxicol Clin Toxicol* 32:487-501.
- Meggs, W.J. 1995. Multiple chemical sensitivities--chemical sensitivity as a symptom of airway inflammation *J.Toxicol.Clin.Toxicol.* 33:107-110.
- Meggs, W.J. 1995. Neurogenic switching: a hypothesis for a mechanism for shifting the site of inflammation in allergy and chemical sensitivity. *Environ Health Perspect* 103:54-56.
- Meggs, W.J., K.A. Dunn, R.M. Bloch, P.E. Goodman, and A.L. Davidoff. 1996. Prevalence and nature of allergy and chemical sensitivity in a general population. *Arch.Environ.Health* 51(4):275-282.

- Meggs, W.J., T. Elsheik, W.J. Metzger, M. Albernaz, and R.M. Bloch. 1996. Nasal pathology and ultrastructure in patients with chronic airway inflammation (RADS and RUDS) following an irritant exposure. *J.Toxicol.Clin.Toxicol.* 34:383-396.
- Meggs, W.J. 1997. Hypothesis for induction and propagation of chemical sensitivity based on biopsy studies. *Environ Health Perspect* 105:473-478.
- Meggs, W.J. 1997. Psychogenic versus biologic basis for chemical sensitivity. *J Allergy Clin Immunol* 100:Pt 1):855-6
- Meggs, W.J. 1999. Mechanisms of allergy and chemical sensitivity. *Toxicol Ind Health* 15:331-338.
- Meggs, W.J. 1999. Gulf War Syndrome, Chronic Fatigue Syndrome, and the Multiple Chemical Sensitivity Syndrome: stirring the cauldron of confusion *Arch Environ Health* 54:309-311.
- Mieir DO, Schlatter MS Frischknecht P. 1999. Selected phenolic compounds in cultivated plants: Ecologic functions, health implications and modulation by pesticides. *Environmental Health Perspectives* 107(Suppl 1):109-114.
- Miller, C.S. and N.A. Ashford. 1992. Allergy and Multiple Chemical Sensitivities Distinguished. In *Multiple Chemical Sensitivities: Addendum to Biologic Markers in Immunotoxicology*. Anonymous National Academy Press, Washington, D.C. 47-63.
- Miller, C.S. 1992. Possible models for multiple chemical sensitivity: conceptual issues and role of the limbic system. *Toxicol.Ind.Health* 8:181-202.
- Miller, C.S. and N.A. Ashford. 1993. The hypersusceptible individual. *Proc Indoor Air '93* 1:549-554.
- Miller, C.S. 1994. White paper: Chemical sensitivity: history and phenomenology. *Toxicol.Ind.Health* 10:253-276.
- Miller, C.S. and H.C. Mitzel. 1995. Chemical sensitivity attributed to pesticide exposure versus remodeling. *Arch.Enviroin.Health* 50:119-129.
- Miller, C.S. 1996. Chemical sensitivity: symptom, syndrome or mechanism for disease?. *Toxicology* 111:69-86.
- Miller, C.S. 1997. Toxicant-induced loss of tolerance--an emerging theory of disease? *Environ Health Perspect* 105:445-453.
- Miller, C.S. 1999. Are we on the threshold of a new theory of disease? Toxicant-induced loss of tolerance and its relationship to addiction and abidction. *Toxicol Ind Health* 15:284-294.
- Miller, C.S., R.B. Gammage, and J.T. Jankovic. 1999. Exacerbation of chemical sensitivity: a case study. *Toxicol Ind Health* 15:398-402.
- Miller, C.S. and T.J. Prihoda. 1999. A controlled comparison of symptoms and chemical intolerances reported by Gulf War veterans, implant recipients and persons with multiple chemical sensitivity. *Toxicol Ind Health* 15:386-397.
- Miller CS. Ashford NA. 2000. Mass psychogenic illness attributed to toxic exposure at a high school. *New England Journal of Medicine.* 342(22):1673.
- Miller CS. 2001. The compelling anomaly of chemical intolerance. *Annals of the New York Academy of Sciences.* 933:1-23.
- Miller CS. 2001. Toxicant-induced loss of tolerance. *Addiction.* 96(1):115-37.
- Mitchell F, ed. *Multiple Chemical Sensitivity: A Scientific Overview*. Atlanta: US Department of Health and Human Services, Public Health Services Agency for Toxic Substances and Disease Registry; 1995.
- Mooser SB. 1987 The epidemiology of multiple chemical sensitivities (MCS). *Occup Med.;*2:663– 681.

National Research Council, Board of Environmental Studies and Toxicology. *Workshop on Health Risks from Exposure to Common Indoor Household Products in Allergic or Chemically Diseased Persons*, July 1, 1987.

Nethercott JR, Davidoff LI, Curbow B. 1993. Multiple Chemical Sensitivities Syndrome: towards a working case definition. *Archives of Environmental Health*. 48(1): 19-26

NOHSC. 1995. Exposure standards for atmospheric contaminants in the occupational environment. AGPS, Canberra.

Powell, J J et al. 1999. Evidence For The Role Of Environmental Agents in the Initiation or Progress of Autoimmune Conditions. *Environmental Health Perspectives* 107(Suppl 5): 667-672

Rea, W.J., I.R. Bell, C.W. Suits, and R.E. Smiley. 1978. Food and chemical susceptibility after environmental chemical overexposure: case histories. *Ann.Allergy* 41:101-109.

Rea, W.J. 1988. Chemical hypersensitivity and the allergic response. *Ear.Nose.Throat.J* 67:50-56.

Rea, W.J. and G.H. Ross. 1989. Food and chemicals as environmental incitants. *Nurse Pract.* 14:17-8, 28, 30 passim.

Rea, W.J. and G.H. Ross. 1991. Food and chemicals as environmental incitants. *Bol. Asoc. Med.P.R.* 83:310-315.

Rea, W.J., Y. Pan, and A.R. Johnson. 1991. Clearing of toxic volatile hydrocarbons from humans. *Bol.Asoc.Med.P.R.* 83:321-324.

Rea, W.J., G.H. Ross, A.R. Johnson, R.E. Smiley, and E.J. Fenyves. 1991. Chemical sensitivity in physicians.. *Bol Asoc Med P R* 83:383-388.

Rea, W.J., G.H. Ross, A.R. Johnson, R.E. Smilley, D.E. Sprague, E.J. Fenyves, and N. Samadi. 1991. Confirmation of chemical sensitivity by means of double-blind inhalant challenge of toxic volatile chemicals. *Bol.Asoc.Med.P.R.* 83:389-393.

Rea, W.J. 1991. Environmental pollutants. *Bol.Asoc.Med.P.R.* 83:278-279.

Rea, W.J., A.R. Johnson, G.H. Ross, J.R. Butler, E.J. Fenyves, J. Griffith, and J.L. Laseter. 1992. Considerations for the diagnosis of chemical sensitivity. In *Multiple Chemical Sensitivities: Addendum to Biologic Markers in Immunotoxicology*. Anonymous National Academy Press, Washington DC. 169-192.

Rea, W J. 1998 *Chemical Sensitivity*. vols 1 - 4. CRC Press, Boca Raton, Fla. V. 1 - principles and mechanisms ; v. 2 - sources of total body load; v. 3 - clinical manifestations of pollutant overload; v. 4 - Tools of diagnosis and methods of treatment

Rea WJ, Fenyves EJ, Seba D, Pan Y. 2001. Organochlorine pesticides and chlorinated hydrocarbon solvents in the blood of chemically sensitive patients [corrected]. A statistical comparison with therapeutic medication and natural hormones. *Journal of Environmental Biology*. 22(3):163-9.

Read, D. 2002. Multiple Chemical Sensitivities. New Zealand Environmental Risk Management Authority.

Reid S, Hotopf M, Hull L, Ismail K, Unwin C and Wessely S., 2002. Reported chemical sensitivities in a health survey of United Kingdom military personnel. *Occup. Environ. Med.* 2002;59;196-198doi:10.1136/oem.59.3.196

Ross, G.H. 1992. History and clinical presentation of the chemically sensitive patient. *Toxicol.Ind.Health* 8:21-28.

Ross, G.H. 1992. Treatment options in multiple chemical sensitivity. *Toxicol.Ind.Health* 8:87-94.

Ross, H.L. 1995. The behavioral effects of indoor air pollutants. *Occup.Med.* 10:147-166.

- Ross, G.H. 1997. Clinical characteristics of chemical sensitivity: an illustrative case history of asthma and MCS. *Environ Health Perspect* 105:437-431.
- Ross, G.H., W.J. Rea, A.R. Johnson, D.C. Hickey, and T.R. Simon. 1999. Neurotoxicity in single photon emission computed tomography brain scans of patients reporting chemical sensitivities. *Toxicol Ind Health* 15:415-420.
- Ross, P.M., J. Whysner, V.T. Covello, M. Kuschner, A.B. Rifkind, M.J. Sedler, D. Trichopoulos, and G.M. Williams. 1999. Olfaction and symptoms in the multiple chemical sensitivities syndrome. *Prev Med* 28:467-480.
- Ross GH, Rea WJ, Johnson AR, Hickey DC, Simon TR. 1999. Neurotoxicity in single photon emission computed tomography brain scans of patients reporting chemical sensitivities. *Toxicology & Industrial Health*. 15(3-4):415-20.
- Royal Australian College of Physicians. 2002. Chronic Fatigue Syndrome Clinical Practice Guidelines. www.mja.com.au/public/guides/cfs/cfs2.html
- RYAN, C M et al. 1988 Cacosmia and neurobehavioural dysfunction associated with occupational exposure to mixtures of organic solvents. *American Journal of Psychiatry* 145:11, November pp.1442-1445
- Saito, Mariko; Kumano, Hiroaki; Yoshiuchi, Kazuhiro; Kokubo, Naomi; Ohashi, Kyoko; Yamamoto, Yoshiharu; Shinohara, Naohide; Yanagisawa, Yukio; Sakabe, Kou; Miyata, Mikio; Ishikawa, Satoshi; Kuboki, Tomifusa, 2005. Symptom Profile of Multiple Chemical Sensitivity in Actual Life. *American Psychosomatic Society Volume 67(2)*, March/April 2005, pp 318-325
- Silberschmidt, M. 2005. Multiple Chemical Sensitivity, MCS. Danish Ministry of the Environment, Environment Protection Agency. www.miljoestyrelsen.dk
- Sorg, B. A. (1999) Multiple chemical sensitivity: potential role for neural sensitization. *Crit. Rev. Neurobiol.* 13, 283–316
- Parliament of South Australia. 2005. Inquiry into Multiple Chemical Sensitivity. Social Development Committee, Twenty Second Report.
- UK Department of Work and Pensions Decision Makers Guide volume 11, chapter 66 www.dwp.gov.uk/publications/dwp/dmg
- United Kingdom. Royal Commission on Environmental Pollution. 2005. 24th Report. Chemicals in products. www.rcep.ok.org
- United States. Environmental Protection Agency. 1999. Recognition and Management of Pesticide Poisoning. 5th Ed. <http://www.epa.gov/pesticides/safety/healthcare>
- Voorhees R. 1997 Results of Analyses of Multiple Chemical Sensitivities Questions. New Mexico Behavioral Risk Factor Surveillance Systems. New Mexico Department of Health, Office of Epidemiology;25.
- Weir, E. 2002 Identifying and managing adverse environmental health effects: a new series. *CMAJ*; 166 (8)
- Weinhold, B. 2001. Making Health Care Healthier. *Environmental Health Perspectives*. 109(8):A370 - A 377
- Winder, C. 1994 Chemically related chronic fatigue syndrome. *Journal of Occupational Medicine and Toxicology*
- Wilson DH, Adams RJ, Tucker G, Appleton S, Taylor AW and Ruffin RE. 2006. Trends in asthma prevalence and population changes in South Australia, 1990–2003. *MJA*; 184 (5): 226-229

Ziem, G and McTamney, J. 1997. Profile Of Patients With Chemical Injury And Sensitivity. Environmental Health Perspectives 105 (Supplement 2):417-436.

Ziem G. 1999. Profile of Patients with chemical Injury and Sensitivity, Part II. International Journal of Toxicology 18:401-490

APPENDIX A. MCS Definitions

Silberschmidt, M. 2005. Multiple Chemical Sensitivity, MCS. Danish Ministry of the Environment, Environment Protection Agency. www.miljoestyrelsen.dk

Proposed Definitions for Multiple Chemical Sensitivity (MCS) since 1985.	
1985	ad hoc Committee, Ontario Ministry of Health: More than 3 months duration Multisystem disorder; Intolerance to foods, chemicals, environmental agents at levels generally tolerated by majority. No objective physical findings: no consistently altered laboratory test; Symptoms diminish with avoidance; recur with exposure.
1987	Cullen: Multiple chemical sensitivities is an acquired disorder characterized by recurrent symptoms, referable to multiple organ systems, occurring in response to demonstrable exposure to many chemically unrelated compounds at doses far below those established in the general population to cause harmful effects. No single widely accepted test of physiologic function can be shown to correlate with symptoms.
1991	Ashford and Miller The patient with multiple chemical sensitivities can be discovered by removal from the suspected offending agents and by rechallenge, after an appropriate interval, under strictly controlled environmental conditions. Causality is inferred by the clearing of symptoms with removal from the offending environment and recurrence of symptoms with specific challenge.
1992	American Academy of Environmental Medicine: Ecologic illness is a chronic multi-system disorder, usually polysymptomatic, caused by adverse reactions to environmental incitants, modified by individual susceptibility and specific adaptation. The incitants are present in air, water, food, drugs, and our habitat.
1992	National Research Council (NRC), Workshop on Multiple Chemical Sensitivities, Working Group on Research Protocol for Clinical Evaluation: Symptoms or signs related to chemical exposures at levels tolerated by the population at large that are distinct from such well recognized hypersensitivity phenomena as IgE-mediated immediate hypersensitivity reactions, contact dermatitis, and hypersensitivity pneumonitis. Sensitivity may be expressed as symptoms and signs in one or more organ systems Symptoms and signs wax and wane with exposures. It is not necessary to identify a chemical exposure associated with the onset of the condition. Preexistent or concurrent conditions (e.g., asthma, arthritis, somatization disorder, or depression) should not exclude patients from consideration.
1992	Association of Occupational and Environmental Clinics: Workshop on Multiple Chemical Sensitivity, Working Group on Characterizing Patients: A change in health status identified by the patient Symptoms triggered regularly by multiple stimuli Symptoms experienced for at least 6 months A defined set of symptoms reported by patients Symptoms that occur in three or more organ systems Exclusion of patients with other medical conditions (psychiatric conditions are not considered exclusionary).
1993	Nethercott et al.:

	<p>The symptoms are reproducible with exposure. The condition is chronic. Low-level exposure results in manifestations of syndrome. Symptoms improve or resolve when incitants are removed. Responses occur to multiple, chemically unrelated substances.</p>
1995	<p>Kurt: The symptoms are "odor-triggered" and "exposure perceived" at very low levels, but are manifest as a multitude of neurobehavioral symptoms that correspond to the accepted definitions of panic disorder. (Kurt, TL. 1995. Multiple Chemical Sensitivities: a syndrome of psuedotoxicity manifest as exposure perceived symptoms. <i>Clin Toxicol</i> 33(2): 101-05, 1995</p>
1996	<p>International Program on Chemical Safety (IPCS): An acquired disorder with multiple recurrent symptoms; associated with diverse environmental factors tolerated by the majority of people; not explained by any known medical or psychiatric disorders.</p>

Silberschmidt, M. 2005

APPENDIX B: EHP Supplement Volume 105 Supplement 2, March 1997. Experimental Approaches to Chemical Sensitivity

Overview

- ◆ Howard Kipen and Nancy Fiedler, p. 405 Chemical Sensitivity: The Scientific Literature
- ◆ Nancy Fiedler and Howard Kipen p. 409 Clinical Perspectives
- ◆ Profile of Patients with Chemical Injury and Sensitivity Grace Ziem and James McTamney p. 417
- ◆ Clinical Characteristics of Chemical Sensitivity: An Illustrative Case History of Asthma and MCS Gerald H. Ross p. 437

Commentary:

- ◆ Laboratory Testing of the Patient with Multiple Chemical Sensitivity Howard R. Kehrl p. 443

Theoretical Perspectives

- ◆ Toxicant-induced Loss of Tolerance--An Emerging Theory of Disease? Claudia S. Miller p. 445
- ◆ Evolving Concepts of Chemical Sensitivity Robert C. MacPhail p. 455
- ◆ Individual Differences in Neural Sensitization and the Role of Context in Illness from Low-level Environmental Chemical Exposures Iris R. Bell, Gary E. Schwartz, Carol M. Baldwin, Elizabeth E. Hardin, Nancy G. Klimas, John P. Kline, Roberto Patarca, and Zhi-Ying Song p. 457
- ◆ Potential Role of Stress and Sensitization in the Development and Expression of Multiple Chemical Sensitivity Barbara A. Sorg and Balakrishna M. Prasad p. 467
- ◆ Hypothesis for Induction and Propagation of Chemical Sensitivity Based on Biopsy Studies William J. Meggs p. 473
- ◆ Psychophysiological Hypotheses Regarding Multiple Chemical Sensitivity Syndrome Paul M. Lehrer p. 479
- ◆ Commentary: Systematic Considerations in the Area of Multiple Chemical Sensitivity Vernon A. Benignus p. 485

Experimental Methods

- ◆ Experimental Strategies for Research on Multiple Chemical Sensitivity Bernard Weiss p. 487
- ◆ Cognitive and Psychomotor Performance Tests and Experiment Design in Multiple Chemical Sensitivity Anthony Wetherell p. 495
- ◆ A Behavior-Genetic Approach to Multiple Chemical Sensitivity David B. Newlin p. 505
- ◆ Human Drug Discrimination and Multiple Chemical Sensitivity: Caffeine Exposure as an Experimental Model Thomas Eissenberg and Roland R. Griffiths p. 509

Working Group Reports

- ◆ Empirical Approaches for the Investigation of Toxicant-induced Loss of Tolerance Claudia Miller, Nicholas Ashford, Richard Doty, Mary Lamielle, David Otto, Alice Rahill, and Lance Wallace p. 515
- ◆ Pavlovian Conditioning and Multiple Chemical Sensitivity Shepard Siegel and Richard Kreutzer p. 521
- ◆ Psychoneuroimmunology Nicholas Cohen, Howard Kehrl, Birgitta Berglund, Ann O'Leary, Gerald Ross, James Seltzer, and Clifford Weisel p. 527
- ◆ Neurogenic Inflammation: With Additional Discussion of Central and Perceptual Integration of Nonneurogenic Inflammation Rebecca Bascom, William J. Meggs, Mark Frampton, Kenneth Hudnell, Kaye Killburn, Gerd Kobal, Michelle Medinsky, and William Rea p. 531
- ◆ Testing the Neural Sensitization and Kindling Hypothesis for Illness from Low Levels of Environmental Chemicals Iris R. Bell, John Rossi III, Mary E. Gilbert, Gerd Kobal, Lisa A. Morrow, David B. Newlin, Barbara A. Sorg, and Ronald W. Wood p. 539

APPENDIX C. Recommended guidance notes for physicians (Ashford & Miller. 1998).

Develop an understanding of MCS. Become acquainted with the symptoms most commonly attributed to it and include it in your differential diagnosis. Be aware that many MCS patients also report various food, alcohol, caffeine, and medications intolerances and ask about these.

Take a careful exposure history paying particular attention to the time each symptom began and exposures that may have preceded onset of illness, such as a chemical spill, fire, pesticide application, remodeling or moving to a new home or office.

Explain to the patient the current controversy in the medical profession about MCS, in particular whether it is psychogenic, toxicogenic or a combination of these. Discuss the fact that more research is needed before the mechanism(s) underlying the condition is understood and before specific therapies targeting that mechanism(s) are tested and shown to be effective.

Determine whether a judicious trial of avoidance and re-exposure might help clarify whether exposures at work or home could be causing symptoms. In a patient who has only recently become ill, consider whether ongoing exposures may need to be interrupted to prevent possible long-term disability.

Encourage the patient to become a careful observer by keeping a diary of symptoms and exposures, including both inhalants and ingestants and noting any consistent relationships between them.

Explain that psychological support sometimes can be a useful therapeutic adjunct, as for any illness. MCS can disrupt career lifestyle, and relationships, placing enormous stress on these individuals and their families.

Discuss the range of treatments that have been used by patients with MCS and the lack of scientific evidence to support their use. Point out potentially harmful aspects of therapies that are unproven or lack a scientific basis.

Describe treatment options and the potential risks and benefits of each, empowering the patient to choose among acceptable options.

When introducing new medications, be especially watchful for new symptoms that may signal an adverse drug reaction.

Telling a patient to avoid exposures that trigger symptoms may not be enough. On a trial basis, have the patient minimize nonessential exposures to fragrances, cleaners, and other products that release volatile organic chemicals.

Understand that a patient who smokes or uses alcohol or caffeine on a regular basis or who has ongoing chemical exposures may have difficulty discerning the relationships between exposures and symptoms.

APPENDIX D. MCS CASE HISTORIES

Case one

Mary W grew up on a farm and has a history of pesticide exposure. Mary worked as a nurse until the sterilising agents caused her health problems. She re trained in another profession and was subsequently employed by a government department. Mary was subject to a chemical (solvent) spill in her workplace which resulted in the building being evacuated and staff members transported to hospital. Some have not recovered to this day. Later in another workplace a pesticide treatment permeated the building which had to be evacuated with some staff being transported to hospital.

Mary is now severely sensitive to solvents and pesticides. She is currently unable to work and support herself or take part in society. She has to wear a respirator when she leaves home. Worsening air levels in the inner suburbs resulted in Mary relocating to an outer city suburb with lower pollution levels some years ago. That suburb is now well developed and heavily polluted.

In recent years, a carpet factory in her area caught fire and caused Mary further health damage. She is severely allergic to most chemicals, foods, nutritional supplements and medications. She is severely sensitive to pesticides and fragrances and is constantly ill, she can smell fragrances used by her neighbours as they drift across the fence line and permeate her house. This exposure keeps her ill with migraines, respiratory problems, digestive problems.

Mary urgently requires hospital care due to ongoing and severe digestive problems but cannot access this care (1) due to her pesticide and fragrance allergies because health care facilities are not pesticide or fragrance free; and (2) she is also severely allergic to many medications, anaesthetics, and the preparations and antibacterial agents used in the procedure she requires.

Her last attempt to have this essential procedure resulted in a medical emergency and she was discharged from the hospital untreated as the specialist refused to deal with her allergy problems.

Mary is unable to eat a balanced diet and is now very emaciated. Sometimes when she goes to the shops or banks etc she passes out. She is in urgent need of medical care but her MCS is not recognised/accepted and several hospitals have sent her home untreated in the last 6 months. One doctor referred her to an immunologist who was supposed to refer her on for dietetic assessment. However, he commented on her respirator and decided she was a psychiatric case. She was never referred to an allergy dietician to assist with her food allergy and food chemical sensitivity. She is struggling to survive.

Case two

Dana has a background of allergic disease and digestive disorders from childhood.

As a child and teenager she was an athlete and spent many hours training in the local swimming pool that was heavily chlorinated.

Her Father was a French polisher by trade and she was constantly exposed to paint.

At 15 years of age, Dana was referred to a dermatologist for eczema. Some of the patch tests that were positive were fragrances and metals. Dana is unable to wear cosmetics or use personal care products.

Dana worked in a research facility where the smell of chemicals was always very strong on the premises. Her absenteeism rate was high largely with upper respiratory allergy and migraine. She has a very high body burden of organochlorine pesticides, solvents and plasticisers and is now unable to work due to her sensitivity to many chemicals.

Dana suffers severe food allergy and phenolic sensitivities, has very sensitive skin and cannot use detergents, disinfectants, washing powders and other laundry aids. She is also unable to tolerate wool or synthetic fabrics on her skin. She can only wear cotton and silk provided these are not dyed with strong colours.

Dana has severe drug sensitivities and has reacted severely to anaesthetic (heart stopped).

She now lives in an area with coastal wetlands and suffers badly when pesticide treatments are under way.

In the last fifteen years, her health has been further damaged by two chemical fires in close proximity. One fire was a pesticide storage facility; the other was a grass fire which set fire to a fence formed from old car tyres. This fire has permanently damaged her lungs.

In a neighbouring suburb, there is an industrial estate that has toxic waste disposal; asphalt plant, CCA timber treatment plant; oil recycling, tannery. There are always fumes, especially in the evenings. Some leave her very debilitated.

In recent times (February 2006) Dana was driving down the freeway alongside the swamp when aerial treatment for mosquitos was underway. A helicopter flew over her car and minutes later her car was full of spray drift, her throat began to swell instantly, she broke out in a rash and has been very ill since the incident. Many people report similar problems with spray drift when mosquito control programs are underway alongside the freeway.

Dana has serious neurological problems for which she is unable to get any assistance from the medical profession. She has lost count of the number of times doctors have told her they cannot help her. She is in a great deal of pain which is constantly exacerbated by fragrances, scented candles and incense used by her neighbour.

Case three

Barbara lived in a sugar growing area for many years and was exposed to agricultural chemicals. Her chemical sensitivities became very severe after the family acquired and operated a pest control business. She has allergy that requires ongoing medication, food sensitivities and severe chemical sensitivities, which have destroyed two marriages. She must wear a mask when she leaves her home to protect herself from chemical exposures and as she lives in suburbia, she is subject to noxious fumes that drift across the fence line from her neighbours' laundry detergents and personal care products etc. The result of the chemical drift is severe disabling migraine and joint, muscle pain. The medications she must take in an effort to achieve something that resembles pain relief are causing secondary problems and reducing her life span. She has osteoporosis as a result of prednisone use for her allergies and recently has broken her foot twice. She is unable to achieve disability access to chemical free medical facilities and doctors have decided she is a substance abuser with psychiatric problems because the only medication that will relieve her migraine is morphine. As a result of not being believed she is unable to access adequate pain relief. She has suffered discrimination in a hospital emergency when a doctor tried to remove her mask and treated her in an undignified manner. More recently she has had problems with several neighbours as in desperation she asked them not to use such strongly scented products because they threatened her life and left her in great pain. The neighbours refused to stop using the strongly scented products, as they do not believe the products make her ill. However, in reality these products threaten her life on a daily basis. More recently we suspect the neighbours have been snooping around her property and harassing her by spraying fragrances and other chemicals around the property and near the air conditioner intake to purposely make her ill. Her water supply has been turned off and she has been bullied by one of the neighbours who approached her in an aggressive manner. Barbara is already in crisis accommodation in the public housing system. She is physically disabled and unable to move house and deteriorating on a daily basis. She also does not have the financial resources to relocate even if there was a safer place for her.

Case four

Karen is/was a research scientist with a PhD in Biochemistry/Immunology following twenty years of research and study. During all of this time she worked within research laboratories connected to either Universities, Hospitals or Private Industry initially as a laboratory assistant, then as a research scientist, and finally as a senior research scientist at her last job. In 1992 following years of handling a variety of chemicals Karen developed MCS and by 1993 had to leave her position as a Senior Research Scientist with a Biotechnology Company in Brisbane. In 1995 Karen finally received her Doctorate of Philosophy and although she now has a PhD she cannot use it as she had intended in the medical-scientific field as she is disabled by chemical exposures and cannot leave her isolated property. Having paid into an insurance fund to protect herself financially from work related injury, the insurance company initially provided income and sent Karen to all nature of specialists - respiratory, psychiatric, physicians, as well as receiving monthly reports from her treating doctor. Things went OK until the company Karen had been working for closed down their Research Department, which meant that she had to resign from the company. Once this happened it seemed that the Insurance Company decided to cut off her income support and terminate her policy. They requested that Karen attend consultations with a notorious physician known as the 'Queensland Hatchet Man' because of his involvement in insurance cases that resulted in people losing insurance benefits. Karen was also asked to see a psychiatrist interstate. She refused to go because she is chemically sensitive and is unable to travel in public transport, including aircraft or to stay in hotels. Her reason for refusing to see the Queensland specialist was that she had been sent to see him by the Worker's Compensation Board (WCB) and he had already formed an opinion about her. His opinion was demeaning and derogatory given her scientific credentials and medical research background and was not within his field of expertise. Apart from this, the visit to him would leave her severely debilitated and it would take a long time for her to recover from leaving her 'safe' home environment. The 'Queensland Hatchet Man' is listed as a Toxicology Specialist but his conclusion was based on psychiatry - he concluded "that this woman had MCS if MCS is a synonym for serious psychological disorders". His opinion was used primarily by the WCB to dismiss Karen's case. The fact that his hospital notes and the WCB report did not match was not of any concern to anyone. The insurance company demanded that Karen see him for assessment, but for Karen, going to this doctor was a no win situation. Both the insurance company and Karen already knew what he would report and therefore she would have her case dismissed. Karen was not willing to go through the humiliation! Not to mention the disability. After

much correspondence the insurance company used false evidence - information from someone else's file (different case numbers) - and reports from doctors Karen had never been to see as grounds for closing her case. Any attempts made to have this reviewed were fruitless. Karen has lost her career and been stripped of all income. Karen has had to rearrange her entire life and is effectively unable to participate in, or attend most social events because of her chemical sensitivity. She has been demeaned by some members of the medical fraternity that she once trusted. Various official bureaucrats have dismissed Karen as a crank and she has encountered obstinate resistance from those who have a financial or other vested interest in the continued sale and distribution of chemical irritants. Karen has been failed by and ripped off by lawyers.

APPENDIX E. WHO Bangkok Charter for Health Promotion in a Globalised World

Scope: The Bangkok Charter identifies actions, commitments and pledges required to address the determinants of health in a globalized world through health promotion.

Effective interventions:

Progress towards a healthier world requires strong political action, broad participation and sustained advocacy.

Health promotion has an established repertoire of proven effective strategies which need to be fully utilized.

Required actions

To make further advances in implementing these strategies, all sectors and settings must act to:

- **advocate** for health based on human rights and solidarity
- **invest** in sustainable policies, actions and infrastructure to address the determinants of health
- **build capacity** for policy development, leadership, health promotion practice, knowledge transfer and research, and health literacy
- **regulate and legislate** to ensure a high level of protection from harm and enable equal opportunity for health and well-being for all people
- **partner and build alliances** with public, private, nongovernmental and international organizations and civil society to create sustainable actions.

Key commitments

The four key commitments are to make the promotion of health:

- central to the global development agenda
- a core responsibility for all of government
- a key focus of communities and civil society
- a requirement for good corporate practice.

1. Make the promotion of health central to the global development agenda

Strong intergovernmental agreements that increase health and collective health security are needed. Government and international bodies must act to close the health gap between rich and poor. Effective mechanisms for global governance for health are required to address all the harmful effects of:

- trade
- products
- services, and
- marketing strategies.

Health promotion must become an integral part of domestic and foreign policy and international relations, including in situations of war and conflict.

This requires actions to promote dialogue and cooperation among nation states, civil society, and the private sector. These efforts can build on the example of existing treaties such as the World Health Organization Framework Convention for Tobacco Control.

2. Make the promotion of health a core responsibility for all of government

All governments at all levels must tackle poor health and inequalities as a matter of urgency because health is a major determinant of socioeconomic and political development. Local, regional and national governments must:

- give priority to investments in health, within and outside the health sector
- provide sustainable financing for health promotion.

To ensure this, all levels of government should make the health consequences of policies and legislation explicit, using tools such as equity-focused health impact assessment.

3. Make the promotion of health a key focus of communities and civil society

Communities and civil society often lead in initiating, shaping and undertaking health promotion. They need to have the rights, resources and opportunities to enable their contributions to be amplified and sustained. In less developed communities, support for capacity building is particularly important.

Well organized and empowered communities are highly effective in determining their own health, and are capable of making governments and the private sector accountable for the health consequences of their policies and practices.

Civil society needs to exercise its power in the marketplace by giving preference to the goods, services and shares of companies that exemplify corporate social responsibility.

Grass-roots community projects, civil society groups and women's organizations have demonstrated their effectiveness in health promotion, and provide models of practice for others to follow.

Health professional associations have a special contribution to make.

4. Make the promotion of health a requirement for good corporate practice

The corporate sector has a direct impact on the health of people and on the determinants of health through its influence on:

- local settings
- national cultures
- environments, and
- wealth distribution.

The private sector, like other employers and the informal sector, has a responsibility to ensure health and safety in the workplace, and to promote the health and well-being of their employees, their families and communities.

The private sector can also contribute to lessening wider global health impacts, such as those associated with global environmental change by complying with local national and international regulations and agreements that promote and protect health. Ethical and responsible business practices and fair trade exemplify the type of business practice that should be supported by consumers and civil society, and by government incentives and regulations.

Call for action

Conference participants request the World Health Organization and its Member States, in collaboration with others, to allocate resources for health promotion, initiate plans of action and monitor performance through appropriate indicators and targets, and to report on progress at regular intervals. United Nations organizations are asked to explore the benefits of developing a Global Treaty for Health.

Prepared by Dr Sharyn Martin, PhD and Dorothy M. Bowes for ASEHA Qld Inc May 2006