



An Integrative Approach to Environmental Intolerances: Multiple Chemical Sensitivity and Related Illnesses

Background

With increased prevalence of chronic disease, a number of illnesses attributed to environmental exposures have arisen. These include:¹

- Multiple chemical sensitivity (MCS)
- Sick building syndrome
- Post 9/11 syndrome
- Silicone breast implant intolerance
- Gulf War syndrome
- Toxic mold syndrome
- Electromagnetic field intolerance.

These highly controversial diagnoses are often classed as functional somatic syndromes. People with these illnesses:²

- Experience suffering, symptoms and disabilities greater than any measurable tissue abnormality
- Tend to be highly involved in self-diagnosis
- Find it difficult to be reassured by others about their illness
- Are more likely to seek out explanations for common symptoms
- Tend to be suspicious of health care providers or to seek providers who share their belief systems
- Place much more importance on biomedical over psychosocial explanations for their symptoms
- Struggle more with mental health issues.

Because these illnesses can be quite disabling at many levels, with a high negative impact on daily functioning, ability to work, and healthcare costs, it is vital for healthcare providers to know how best to help people who experience them.

This handout will focus primarily on multiple chemical sensitivity (MCS) as the best-studied of these environmental illnesses, but the principles underlying etiology, diagnosis and treatment are quite similar for all of them.

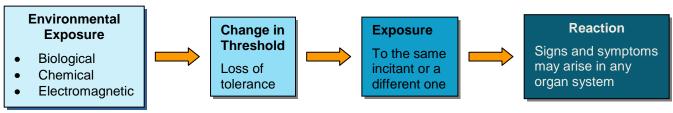
Multiple Chemical Sensitivity – The Quintessential Environmental Intolerance

Multiple Chemical Sensitivity (MCS) is also known as idiopathic environmental illness (IEI), toxicantinduced loss of tolerance (TILT), twentieth century disease, chemical AIDS, ecological illness, and total allergy syndrome, among other names. A 2003 study of 1,582 individuals from the Atlanta area found that 12.6% reported a hypersensitivity to common chemicals. Of that 12.6%, 13.5% of them (1.8% of the total sample) reported having lost their jobs because of their sensitivities.³ Another 2003 study found that the average person with MCS in a sample of 917 self-reported cases spent an average of \$51,000 on health care, \$7,000 in the past year.⁴



MCS arises after exposure to a chemical or chemicals in the environment. Some people report symptoms after just one exposure, and others develop them after multiple exposures. After these first exposures (often referred to as the initiation phase), they find that other chemicals can cause symptoms as well. This is called the elicitation phase.

PATTERN OF ONSET FOR ENVIRONMENTAL INTOLERANCES



Typical chemicals that people blame for their symptoms include:³

- Appliances (87%)
- Ink (70%)
- Chlorine/water (55%)
- Furniture (54%)
- New carpet (38%)
- Salon products (33%)
- Outdoor parks (22%)
- Exhaust fumes (20%)
- Tobacco (17%)
- Pesticides (15%)
- Cleaners (12%)

Most common symptoms people will describe include:³

- Headache (88%)
- Burning eyes (77%)
- Difficulty breathing/asthma (59%)
- Nausea/GI (55%)
- Dizziness (46%)
- Concentration problems/mental fog (32%)
- Muscle pain (30%)
- Fever (17%)
- Unconsciousness (7%)
- OTHER (51%) these include fatigue, forgetfulness, irritability, sneezing, hoarseness, palpitations, insomnia, memory loss, euphoria, and urinary symptoms

MCS is highly controversial. It has not been accepted as an established organic disease by the World Health Organization, the American Academy of Allergy and Immunology, the American Medical Association, the American College of Occupational and Environmental Medicine, the American College of Physicians, or the International Society of Regulatory Toxicology and Pharmacology.⁵ This leaves people with MCS struggling to find the right team of health care providers to help them with their symptoms.



Causes of Multiple Chemical Sensitivity and Other Environmental Intolerances

There is heated debate in the medical community about the etiology of MCS. It has been argued that MCS is a mind-body syndrome, and it is not sufficient to try to provide either a strictly physical or a strictly psychological explanation of symptoms. Research points to several potential causes, though most recently, a link with various behavioral patterns or mental health symptoms has been increasingly favored. Some of the most popular theories about how MCS might occur include:

- 1. <u>Toxicant-Induced Loss of Tolerance (TILT)</u>. This perspective is especially popular with practitioners of environmental medicine. It is posited that each of us has a threshold in terms of our ability to bear environmental toxins, but that for people with sensitivities, that threshold is surpassed, leading to illness.^{5,6}
- Neurogenic inflammation/sensitization. It seems that with chemical exposure, people with MCS have nerve fibers that are more likely to cause inflammation in various parts of the body. One potential mechanism centers on the N-methyl-D-aspartate neuroreceptors becoming hypersensitive after repeated exposure to organic solvents, which leads to elevated levels of peroxynitrites and oxides.⁷
- 3. <u>Altered neurotransmission between the olfactory, memory, and emotional centers</u> <u>of the brain</u>. Some people seem to be more prone to the creation of a pattern where smells will cause very strong emotions. The brain remembers a smell that causes problems and will then respond to other smells as well. People with MCS display different findings from controls on imaging studies like MRI and PET scans when they are exposed to certain smells.⁸

It has also been theorized (no specific studies) that the vomeronasal organ may be connected to chemical sensitivities. It is a small tubular organ, located at the bottom of each nostril, that serves as part of a sensitive chemosensory system in animals.⁹

Some studies have suggested that chronic nasal mucosal inflammation might increase sensitivity to chemicals by allowing passage of inflammatory compounds into the nasal passages. People with chemical sensitivities have defective tight junctions between cells.¹⁰

- 4. <u>Bioassociation</u>. Conditioning, or bioassociation, was first described by Pavlov, who measured saliva production in dogs when he rang a bell. At first he would ring a bell when he gave them food, and they would salivate. After being 'conditioned' to associate the bell with the food, they would salivate anytime someone rang the bell, whether there was food or not. Some propose that bioassociation occurs in a more complex fashion with MCS. A person experiences a symptom in the presence of a given chemical or odor, and then the symptom arises again when a similar chemical exposure occurs, even if it is not the same chemical that caused the original symptoms.¹¹
- 5. <u>Stress</u>. A survey of 10,275 people found that environmental intolerance was correlated with more stress in daily life, a strained work situation, sustained arousal, and a tendency toward more subjective health complaints.¹²



6. <u>Other psychological health factors</u>. The 2008 German MCS-Multicentre Study, which included 291 environmental medicine outpatients, concluded, "Our results do not support the assumption of a toxicogenic-somatic basis of the MCS phenomenon. In contrast, numerous indicators for the relevance of behavioural accentuations, psychic alterations, or psychosomatic components were found..."¹³

Similarly, Bailer and colleagues found that ½ of a group of 54 subjects with sensitivities (those with the most intense symptoms) met DSM-IV criteria for somatoform disorder. Those with fewer symptoms still had "...higher trait anxiety, more of a focus on autonomic sensations, and more pronounced somatic symptom attributions." ¹⁴ For a summary of similar studies in this area, see Bailer, Withoft, and Rist's 2008 article.¹⁵

No link between traumatic past experiences and environmental intolerances was found in a 2007 study.¹⁶ A 2006 review of provocation studies and MCS patients concluded that, based on the combined findings from 37 studies, "...persons with MCS do react to chemical challenges; however these responses occur when they can discern differences between active and sham substances, suggesting that the mechanism of action is not specific to the chemical itself and might be related to expectations and prior beliefs."¹⁷

One small study did note that when patients with MCS are surveyed when they are not experiencing exposures or symptoms, they score normally on mental health surveys, as compared to when they are exposed.¹⁸

7. <u>Genes</u>. MCS does seem to be more likely to be linked with certain genes, including some genes that are also found in people who have panic attacks.¹⁹

It may be that MCS will eventually be found to be a disease with specific causes, but for now, there are still many unanswered questions.

Diagnosis of Multiple Chemical Sensitivity

In research, MCS is defined based on the following:²⁰

- 1. It is chronic symptoms have been present for many months.
- 2. It is reproducible it can be predicted when symptoms will occur.
- 3. Symptoms occur with low levels of chemicals, levels that would not normally be considered toxic to most people.
- 4. Symptoms are triggered by multiple, unrelated chemicals.
- 5. Symptoms disappear when the exposure stops.
- 6. Multiple organ systems are involved.

One way to determine if patients' symptoms are consistent with others with MCS is for them to take the QEESI inventory. Here is a link to a pdf file with this survey: http://www.chemicalsensitivityfoundation.org/chemical-sensitivity-questionnaire.htm



For most environmental intolerance illnesses, self-diagnosis is typical; there is no easy way to confirm that MCS exists through laboratory testing.²¹ People with MCS have decreased lymphocytes, but this also occurs in many people with depression. Various lab results also change, perhaps in response to elevated cortisol, in both MCS and somatization disorders. Some providers recommend ordering other labs⁶ – typically panels not covered by most insurance companies – but there is a lot of debate about how useful and reliable they are. The American Academy of Environmental Medicine, which strongly promotes the use of lab testing for diagnosis and treatment of environmental intolerances, lists a number of tests, which academy members might order for patients. These can be reviewed at: http://www.aaemonline.org/practiceguidelines.html.

Provocation studies tend to be unreliable.¹⁷ Often, in research with people who say they have chemical sensitivities, exposure to neutral things like saltwater can cause the same symptoms if people believe they are being exposed to something harmful. Sometimes, when people are exposed without their knowing to a chemical that they believe causes them problems, they will not have any symptoms. It is possible, however, to sensitize people to chemicals in laboratory settings.⁵ For example, a study may expose healthy volunteers to a certain level of carbon dioxide along with a chemical smell; the carbon dioxide can elicit certain symptoms. Later, when just the odorant is presented, the person will exhibit similar symptoms.

Therapy/Treatment for MCS and Other Environmental Intolerances

Regardless of whether or not these disorders are officially recognized by various groups, and regardless of the etiology, people suffer from them nonetheless. Naturally, healthcare practitioners want to help. Of paramount importance is the question of how that can be accomplished.

Since MCS was first characterized in the 1950s, the American Academy of Clinical Ecology and other groups have arisen. Practitioners who refer to themselves as clinical ecologists or experts in environmental medicine will often apply various unconventional techniques in the treatment of environmental intolerances. Unfortunately, evidence of efficacy for many of these approaches is limited, and they are often quite costly. It is crucial that the risks and benefits of various therapeutic options be openly discussed. Patients should be coached on how to critically evaluate all information they find regarding treatment options. The average person with MCS has seen at least 8-12 providers and reports only 1 in 4 to be at all helpful.⁶ Perhaps there is room for improvement.

Few studies have been done, but there are nonetheless some suggestions that may prove helpful and are likely to be safe. Cost to patients should always be kept in mind. Gibson compiled survey information from 917 people with MCS to see what worked for them out of over 100 different types of treatment.⁴



HELP/HARM RATIO OF TREATMENTS FOR MCS⁴

For each of the therapies listed below, the number represents a ratio of benefit to harm. Higher numbers indicate that more people found benefit, and numbers below one indicate people found the therapy harmful. Remember that the suggestions below are based entirely on subjective responses.

Beneficial Treatments	Help:Harm Ratio	Beneficial Treatments (cont'd)	Help:Harm Ratio
Chemical-free living space	155.2	Aluminum foil to seal off-gassing	6.8
Chemical avoidance	118.6	Massage	6.8
Prayer	48.3	Oxygen therapy	6.4
Meditation	19.2	Reiki	6.4
Acupressure	14.9	Other minerals	6.4
Touch for Health	14.3	Charcoal mask	6.0
Air filters	13.7	Psychotherapy to cope with MCS	6.0
Rotation diet	12.7	IV magnesium	5.8
Acidophilus	12.7	Polarity balancing	5.6
Relocation	11.7	Herbal medicines	5.5
Reflexology	11.6	Other vitamin C (not IV)	5.5
Personal oxygen	10.6	Hatha yoga	5.5
Faith healing	9.3	Vitamin E	5.4
Support group	8.7	Traditional chiropractic	5.3
Craniosacral work	8.6	Acupuncture	5.3
Magnesium supplements	8.6	Qi gong	5.1
Chiropractic w/applied kinesiology	7.5	Milk thistle seed	5.0
Nambudripad desensitization (NAET)	7.1		

Note that the treatments where people had a certain amount of control over the activity or therapy, such as avoidance, prayer, and meditation, have much higher scores. It is important that people with MCS are actively involved in their care and that they are encouraged to look beyond treatments that are just "physical".



<u>Harmful</u> Treatments	Help:Harm Ratio	<u>Harmful</u> Treatments (cont'd)	Help:Harm Ratio
Zoloft	0.1	Xanax	0.6
Prozac	0.3	Microhydrin	0.8
Elavil	0.3	Acyclovir	0.8
Other antidepressants	0.5	Provocation Neutralization with preservative; glutathione nasal spray	0.9
Valium	0.5	UltraClear	1.0
Antiseizure meds other than Neurontin (which was 1.1)	0.5	Hydrogen peroxide	1.0

The following treatments were not viewed as helpful.

Note that medications, in particular, did not score well. It is important to remember that people with MCS tend to have problems with medications. Sometimes, new supplements can be problematic as well. A good rule of thumb for individuals with MCS is to take medications and supplements at 1/4 to 1/2 of recommended dosing. This can be increased if needed and if tolerated.

Reminders for Providers Working with Environmental Intolerance

Needless to say, it is challenging to treat a disorder when:

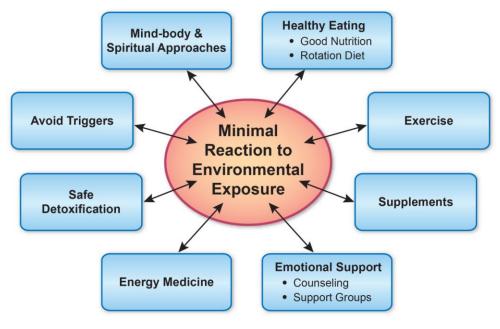
- 1. People debate whether it is truly a disorder and it is not recognized by many medical organizations.
- 2. Its etiology is hotly debated.
- 3. There is no "standard of care" as far as diagnosis or management.

Unfortunately, in an era of increasing chronic disease, this is not an unusual set of circumstances. When dealing with any disorder that might be classed as a functional somatic syndrome, keep the following general guidelines in mind:²

- No matter what illness or problem someone has, they deserve compassionate attention, respect, and honesty from their care provider.
- Start by ruling out diagnosable diseases. As always, a good history and physical are key. Also investigate possible exacerbating conditions, e.g. structural issues such as deviated septum, shift work so not getting enough sleep, etc.
- Be wary of over-ordering diagnostic tests. Part of the pattern with these syndromes is for people to want a biomedical explanation, which may not always be available. Sometimes negative tests can provide reassurance, which has value, but not always.
- Rule out psychosocial causes for the illness. Be cautious about how this is described, reminding the patient that this is part of holistic, individualized care.
- Form a collaborative alliance.
- Make restoration of function the primary goal. How might they move toward getting back to work, or getting out of the house, or being able to regain more activities of daily living?
- Be mindful of resources and expenses for the patient.
- Some data indicates that cognitive behavioral therapy can decrease both distress and symptoms, if patients are willing.



An Integrative Approach to Multiple Chemical Sensitivity



An integrative approach to multiple chemical sensitivity includes holistic treatment focusing on the body, mind, and spirit.

General Treatment Guidelines

The following therapeutic approaches are worth sharing with patients:

- Incorporate a holistic approach. People with MCS often respond well to therapies that look at the whole person – mind, body, emotions, and spirit. Given the complex nature of this illness, this makes sense. Encourage people to explore a variety of possibilities.
- Within reason, avoid the chemicals that cause problems:
 - Change work environment; some people find working at home is easier.
 - Consider an all-electric home (without gas power, fireplaces, etc.).
 - o Minimize volatile organics paints, solvents, nail polish, etc.
 - Choose tile over carpet.
 - Obtain glass and metal furniture without glues.
 - Wear clothing and use home products made from untreated cotton-based fibers and undyed fabrics.
 - Use non-scented products.
 - Allow home items with odors to outgas.
 - Eat organic when able.
 - Allow time. After a year of non-exposure, the sensitivity often resolves (some studies show it happens in less time).
 - Be careful about the effect of these changes on work, family, social life, and nutrition.
 - Let others know in advance what chemicals are problematic (e.g., let people know if you can't tolerate their perfume or cigarette smoke).

PEARLS FOR CLINICIANS



- <u>Join a support group</u>. Encourage them to explore if there is a support group for environmental intolerances in your area and/or give them the our corresponding <u>patient</u> <u>handout</u> that contains links to online support groups.
- <u>Consider prayer and meditation</u>. Explore with patients what gives them a sense of meaning and purpose. Encourage prayer if it is part of their belief system. Many people find that meditation is a powerful approach. Suggest enrollment in a meditation or mindfulness-based stress reduction class. (See our handout <u>Meditation for Health and Happiness</u>.)
- Explore other mind-body therapies. While research is limited, there is some thought that biofeedback can be useful in MCS. People learn how to consciously control the way their bodies respond to exposures. It is important for them to recognize that their symptoms are not usually as dangerous as they seem. For example, a perfume may make a person short of breath, but there are few, if any, reports of a person actually being harmed by that shortness of breath. If the fear tied to the shortness of breath can be overcome, being exposed to the perfume will not be as much of a problem. Hypnosis might also be useful for dealing with MCS. Breathing exercises are another useful way to help the mind to cope with the physical symptoms of MCS. (See our handout <u>Breathing Exercise</u>.) Noticing what triggers a response to a chemical can help a person learn how to have more control over it. Some people with MCS enjoy therapeutic journaling. (See our handout <u>Using Journaling to Aid Health</u>.)
- **Explore emotional health.** Studies have shown that people who have MCS have a high rate of various mental health problems. This is not to say that MCS is "all in a person's head." Rather, it implies that it is VERY important to explore the role of emotions and one's state of mind in influencing symptoms and behaviors. At least half of patients with MCS meet criteria for depression, anxiety, or somatoform disorders, and there are similarities between MCS and post-traumatic stress disorder.²² It is important to address emotional symptoms if they are present. Sometimes a psychiatrist or counselor can be extremely helpful for those with MCS. Cognitive behavioral therapy is one suggested approach.
- **Exercise.** It is important to keep active. If need be, even increasing activity by just a minute or two a day may help people with MCS become more tolerant by helping decrease their inflammatory cytokine levels. Some people find that higher carbon dioxide levels trigger symptoms, so gradually building up the intensity of exercise is wise.
- **Explore energy medicine.** Many people with MCS respond quite dramatically to subtle energy-based therapies. Often, they report being more "in-tune" with energy and emotion than the average person. They might consider acupuncture, healing touch, reiki, homeopathy, acupressure, and other such therapies.
- **Consider a rotation diet.** To what extent foods connect to symptoms in MCS is unclear, but many people find that eliminating or spacing out how often they eat a certain food can help with their symptoms. Many experts recommend a trial rotation diet. To do this, one eats a given food or cluster of foods no more than once every four to seven days. Start the diet with foods eaten less frequently; some people will only eat one food at each meal at first. Have them pay attention to what they crave, because it may be part of the problem. Some people



argue that after six to twelve weeks of avoiding a food, a person will begin to tolerate it again, provided they don't eat it too often. Encourage them to pay close attention to good overall nutrition. A reasonable sample diet can be found online at: http://www.moondragon.org/nutrition/diet/rotationdiet.html

- **Remember your assets.** Many people with MCS can be classified as "Highly Sensitive People." Elaine Aron has written extensively on this in her book *The Highly Sensitive Person*. People with sensitivities often tend to be quite empathic, intuitive, artistic, compassionate, and able to notice details that others miss. If fitting, point out these tendencies and encourage them to make use of these traits.
- **Consider supplements.** Some people benefit from one to two grams of magnesium per day. A vitamin supplement containing vitamins E and C and minerals at RDA amounts is also reasonable. Milk thistle seeds are very safe for use by people; there are no reports in the worldwide research of significant side effects. Start at 1/4 to 1/2 the doses that are usually recommended and increase from there.
- **Only change one thing at a time.** This will allow them and you to identify which approaches work and which do not. Keeping a journal about symptoms and treatments tried can be helpful.
- **Try a safe detoxification regimen.** Again, some with environmental intolerance like this approach. See our handout <u>Detoxification to Promote Health: A 7-Day Program</u> for an example of such a regimen.

As you work together to find the best way to address symptoms, encourage individuals to be patient. Just as different people with MCS are bothered by different things, it is probably true that each person will have a specific set of treatments that work best for him or her. Most people ultimately find a combination of things that gives them the best results.

Web Resources

For more information about MCS and to see popular sites that many patients are reading, check out the following, noting that they represent a wide spectrum of opinions about how to conceptualize and treat environmental intolerance:

United States Department of Labor	Website on MCS	http://www.osha.gov/SLTC/multipleche micalsensitivities/index.html
The Ohio State University Extension	Fact Sheet on MCS	http://ohioline.osu.edu/cd- fact/pdf/0192.pdf
American Family Physician (A journal of the American Academy of Family Physicians)	Review article on MCS	http://www.aafp.org/afp/980901ap/mag ill.html
American Council on Science and Health	Report. (Takes a strongly negative stance on using MCS as a diagnosis.)	http://www.acsh.org/docLib/20040426_ mcs.pdf



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Chemical Injury Information Network (Support and advocacy organization run by people with MCS.)	Website. Provides legal and medical referrals and educational resources. Strongly pro-MCS stance.	http://www.ciin.org/
The Chemical Sensitivity Foundation (Link to a questionnaire validated by Claudia Miller MD, MS of the University of Texas School of Medicine at San Antonio.)	Validated questionnaire The Quick Environmental Exposure and Sensitivity Inventory (QEESI). PDF download. To help identify individuals with multiple chemical intolerances.	http://www.chemicalsensitivityfoundatio n.org/chemical-sensitivity- questionnaire.htm
The Chemical Sensitivity Foundation (Nonprofit corporation whose goal is to raise public awareness about MCS.)	Website	http://www.chemicalsensitivityfoundatio n.org/
The National Academies Press	PDF of on-line book, which includes papers written by participants in a workshop on MCS offered at the request of the Environmental Protection Agency	http://www.nap.edu/openbook.php?isb <u>n=0309047366</u>
Independent Living Research Utilization (ILRU) (A national center for information, training, research, and technical assistance in independent living.)	On-line book Understanding and Accommodating People with Multiple Chemical Sensitivity in Independent Living by Pamela Reed Gibson PhD, James Madison University.	http://www.ilru.org/html/publications/bo okshelf/MCS.html#help1
Maryland Cooperative Extension	Handout. Multiple Chemical Sensitivity (MCS)An Overview Pesticide Information Leaflet No. 21 By Amy E. Brown Ph.D.	http://www.entmclasses.umd.edu/peap /leaflets/pil21.pdf
Multiplechemicalsensitivi ty.org (Website sponsored by Ecos Organic Paints and Biosis Ltd.)	Information and links (some are quite extreme in their views).	www.multiplechemicalsensitivity.org

See our corresponding <u>handout for patients</u> on this topic.



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