

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

### **What are environmental intolerances?**

In recent years, there has been an increase in the number of illnesses that may be caused by a reaction to something in a person's environment. These illnesses include:

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

This handout will focus mainly on **multiple chemical sensitivity (MCS)** because it is the best-studied of these environmental illnesses. But the causes, diagnosis, and treatment are similar for all of them.

### **How does MCS affect people?**

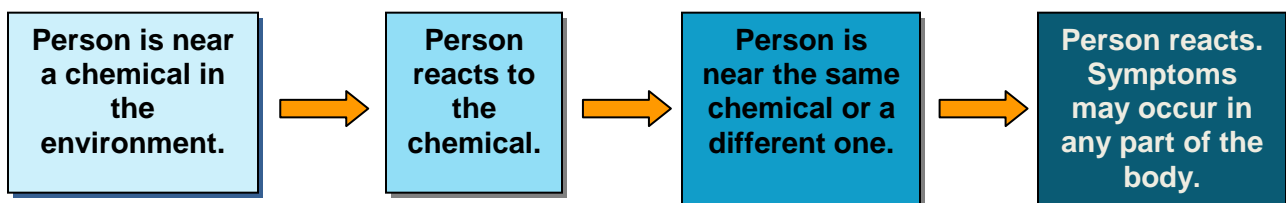
People vary a lot in their reactions. For some people, these illnesses can be quite disabling. They can affect a person's ability to work, accomplish daily tasks, and enjoy leisure activities. They can also increase the cost of healthcare.

A study in 2003 of 1,582 individuals from the Atlanta area found that 12.6% reported being overly sensitive to common chemicals. Of that 12.6%, 13.5% of them (1.8% of the total group) had lost their jobs because of their sensitivities. Another 2003 study of 917 people with MCS, found that on average each spent \$51,000 on health care, \$7,000 in the past year.

### **How does MCS start?**

MCS occurs after a person is near a chemical or chemicals in the environment. Some people report symptoms after just one occurrence. Others develop symptoms after they have been near the substance several times. After these first few times, they find that other chemicals can cause symptoms as well.

#### **HOW MCS BEGINS**





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### **What locations or substances cause symptoms to occur?**

People often blame their symptoms on the following:

- 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%).

### **What are the symptoms of MCS?**

The most common symptoms people describe include:

- Headache (88%)
- Burning eyes (77%)
- Difficulty breathing/asthma (59%)
- Nausea/GI (55%)
- Dizziness (46%)
- Problems concentrating/mental fog (32%)
- Muscle pain (30%)
- Fever (17%)
- Unconsciousness (7%)
- OTHER (51%) – these include fatigue; forgetfulness; irritability; sneezing; hoarseness; heartbeats that are hard, rapid or not regular; difficulty sleeping; memory loss; an exaggerated feeling of happiness; and urinary symptoms.

### **Why is MCS sometimes difficult to treat?**

Doctors and medical associations do not agree on whether or not MCS is an actual disease. This leaves people with MCS struggling to find the right team of health care providers to help them with their symptoms.

### **What causes MCS and other environmental intolerances?**

Clinicians do not agree on the cause of MCS. It has been argued that MCS involves both the mind and body. It may not be strictly a physical disease or strictly a psychological one. Research suggests several potential causes: an overload of chemicals for a sensitive person, inflammation (one of the body's ways of protecting itself, but it is possible to have too much of a good thing), the genes one inherits, stress, anxiety, and previous negative experiences with chemicals. Research may eventually prove that MCS is a disease with specific causes. For now, there are still many unanswered questions.



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### **How is MCS diagnosed?**

Researchers use the following definition of MCS:

1. It is chronic. Symptoms have been present for many months.
2. One can predict when symptoms will occur.
3. Symptoms occur when someone has been near low levels of chemicals. These levels are not a problem for most people.
4. Symptoms are triggered by multiple, unrelated chemicals.
5. Symptoms disappear when the exposure stops.
6. Different parts of the body and multiple organs are affected.

For most environmental intolerance illnesses, patients diagnose themselves. There is no easy way to confirm that a person has MCS through laboratory testing. People with MCS have decreased white blood cells. (White blood cells fight infection and help keep one healthy.) However, this also occurs in many people with depression. Other lab results may also show a change from normal, perhaps due to increased cortisol levels. (Cortisol is a hormone made by the body when a person is stressed.) Again, other disorders involve increased cortisol as well. Some clinicians recommend lab tests that are not usually done. These tests can be expensive and are not covered by most insurance companies. Also, there is a lot of debate among clinicians about how useful and reliable they are.

The QEEI questionnaire can help determine if your symptoms are similar to others who have MCS. QEEI stands for *Quick Environmental Exposure and Sensitivity Inventory*. You can print out a copy at this link: <http://familymed.uthscsa.edu/geesi.pdf>. You may want to discuss your completed questionnaire and the interpretation sheet with your clinician.

### **What treatments are available for MCS and other environmental intolerances?**

MCS was first described in the 1950s. Since that time, some clinicians have focused on this condition. These clinicians refer to themselves as clinical ecologists or experts in environmental medicine. They will often treat environmental intolerances in ways not considered part of usual medical care. Unfortunately, there is little evidence that many of these approaches are helpful. Also they are often quite costly. To avoid spending a lot of money on treatments that will not help, it is important that you discuss the risks and benefits of any treatment you are considering with a clinician whom you trust. Learn how to evaluate all information you find about different treatment options. It is sad to know that the average person with MCS has seen at least 8-12 clinicians and that they report only one in four to be at all helpful.

There has been very little good research to guide the treatment of MCS and similar conditions. In 2003, a group of researchers from James Madison University surveyed 917 people with MCS to see what worked for them out of 101 different types of treatment. The tables on the next two pages show the treatments that people found the most and least helpful.



**HELP/HARM RATIO OF TREATMENTS FOR MCS**

**For each of the therapies listed below, the number is a ratio of benefit to harm. Higher numbers indicate that more people found the treatment helpful. Numbers below one indicate people found the therapy harmful. Remember that these are suggestions from others who have MCS and not the result of clinical trial research.**

<b>Beneficial Treatments</b>	<b>Help:Harm Ratio</b>	<b>Beneficial Treatments (cont'd)</b>	<b>Help:Harm Ratio</b>
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 (a form of energy healing)	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 (bacteria used to make yogurt)	12.7	Polarity balancing (touch and movement to help energy flow)	5.6
Moving to a new location	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 (skull and spine)	8.6	Acupuncture	5.3
Magnesium supplements	8.6	Qi gong (movement, meditation, and breath control)	5.1
Chiropractic w/applied kinesiology	7.5	Milk thistle seed	5.0
Nambudripad desensitization (NAET) (alternative way of treating allergies)	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 to take an active role in your treatment. It is also a good idea to include different types of treatments.



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The following treatments were not viewed as helpful.

<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

Note that people did not find medications, in particular, to be helpful. In general, people with MCS tend to have problems with medications. Sometimes, new supplements can cause problems as well. A good rule of thumb is to take medications and supplements at ¼ to ½ of recommended dosing. This can be increased if needed and if tolerated.

### **What are some hints for working with a clinician to reduce my symptoms?**

Needless to say, it can be very challenging to have a disorder when:

1. clinicians do not agree that it is truly a disorder,
2. it is not clear what causes it, and
3. there is no one “standard of care” to diagnose and manage it.

Start by choosing a primary care clinician with whom you feel comfortable.

- No matter what illness or problem you have, you deserve compassion, attention, respect, and honesty from your clinician. In turn, give these courtesies to your clinician.
- Ask your clinician if you could have a disorder other than or in addition to MCS. It is a good idea for your clinician to gather a thorough medical history from you and to do a careful physical examination.
- Think about anything in your life that could be adding to the problem. Explore these possibilities with your clinician. For example, do you work different shifts, so sometimes you are not sleeping enough or as well? Is there a lot of stress in your personal life or at work? Could an issue such as a deviated septum (when the thin wall between your nostrils is closer to one side rather than in the middle) be making it harder for you to breathe? If you can make some parts of your life better, you will feel better overall.
- Be wary if the clinician wants to order many laboratory tests for MCS. There are currently no good laboratory tests to use for diagnosis. (Note: further testing may be recommended if your clinician suspects that you have a disorder other than MCS.)
- Become a partner with your clinician. Work together to figure out what will reduce your symptoms.
- Set goals to get your life back. What steps can you take to regain more activities of daily living, get out of the house, or get back to work?
- Be careful about questionable remedies, so you do not incur large expenses for treatments that do not help.

### PATIENT HANDOUT



## An Integrative Approach to Multiple Chemical Sensitivity



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

### What are some general treatment guidelines?

The following are some good approaches to consider:

- **Use a holistic approach.** People with MCS often respond well to therapies that look at the whole person – mind, body, emotions, and spirit. Try a variety of possibilities.
- **Exercise.** It is important to keep active. If this is difficult, increase your activity level by just a minute or two a day. This can help your body tolerate chemicals by strengthening your immune system. Some people find that higher carbon dioxide levels (that can occur with exercise) trigger symptoms. To help with this, slowly build up how hard you exercise.



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- **Within reason, avoid the chemicals that cause problems.**
  - Change where you work; some people find working at home is easier.
  - Consider an all-electric home (without gas power, fireplaces, etc.).
  - Minimize chemicals such as paints, solvents, nail polish, etc.
  - Choose tile instead of carpet.
  - Obtain glass and metal furniture without glues.
  - Wear clothing and use home products made from untreated cotton-based fibers and fabrics that are not dyed.
  - Use non-scented products.
  - Allow home items with odors to outgas (i.e., air out) before you use them.
  - Eat organic products when you are 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. (For example, let people know if you can't tolerate their perfume or cigarette smoke).
- **Join a support group.** Learn if there is a support group for environmental intolerances in your area or join an on-line support group. See resource listings on page 9.
- **Consider prayer and meditation.** What in your life gives you meaning and purpose? Use prayer if it is part of your belief system. Many people find that meditation is a powerful approach. Consider taking a meditation or mindfulness-based stress reduction class. (See our handout [\*Meditation for Health and Happiness\*](#).)
- **Explore other mind-body therapies.** While research is limited, biofeedback may be useful in MCS. You may be able to learn how to consciously control the way your body responds to exposures. It is important to recognize that your 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 you can overcome the fear tied to your shortness of breath, being exposed to the perfume will not be as much of a problem. Hypnosis might 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 [\*Breathing Exercise\*](#).) Noticing what triggers your symptoms can help you learn how to have more control over them. Some people with MCS find that keeping track of their symptoms and possible triggers in writing can be helpful. (See our handout [\*Using Journaling to Aid Health\*](#).)
- **Explore your emotions.** Studies have shown that people who have MCS are more likely than others to have a mental health concern. This is not to say that MCS is “all in a person's head.” Rather, it means that it is VERY important to explore how your state of mind may affect your symptoms and behaviors. At least half of patients with MCS meet criteria for depression, anxiety, or disorders with unexplained causes. There are also similarities between MCS and post-traumatic stress disorder. 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 approach to try. It helps people learn how their thoughts and feelings affect their behavior.



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- **Explore energy medicine.** Many people with MCS respond quite dramatically to subtle energy-based therapies. Often, they feel more “in-tune” with energy and emotion than the average person. 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. 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, eat 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. Pay attention to what food you crave. It may be part of the problem. Some people find that after six to twelve weeks of avoiding a food, they will begin to tolerate it again, if they don't eat it too often. Pay close attention to good overall nutrition. A sample diet can be found online at: <http://www.moondragon.org/nutrition/diet/rotationdiet.html>
- **Remember your assets.** Many people with MCS seem to be highly sensitive. They often tend to be quite empathic, intuitive, artistic, compassionate, and able to notice details that others miss. If this describes you, 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 recommended daily amounts is also reasonable.
  - Milk thistle seeds are very safe. Start at ¼ to ½ the dose that is recommended and increase from there.
- **Only change one thing at a time.** This will allow you to learn which new approaches work and which ones do not. It can be helpful to keep a journal about your symptoms and any approaches that you try.
- **Try a safe detoxification regimen.** You may want to consider a safe way to detox your body. See our handout [\*Detoxification to Promote Health: A 7-Day Program\*](#) for an example of such a regimen.

As you work to find the best way to address your symptoms, 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. Over time, most people find a combination of approaches that give them the best results.

### **Web Resources**

See the websites listed on page 9 for support, more information, and a variety of opinions on MCS. Remember to check with your health care provider prior to exploring any remedies suggested on these public sites.





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<b>American Council on Science and Health</b>	Report. (Takes a strongly negative stance on using MCS as a diagnosis.)	<a href="http://www.acsh.org/docLib/20040426_mcs.pdf">http://www.acsh.org/docLib/20040426_mcs.pdf</a>
<b>American Family Physician</b> (A journal of the American Academy of Family Physicians)	Article on MCS in a medical journal.	<a href="http://www.aafp.org/afp/980901ap/mag_ill.html">http://www.aafp.org/afp/980901ap/mag_ill.html</a>
<b>Chemical Injury Information Network</b> (Support and advocacy organization run by people with MCS)	Website. Provides legal and medical referrals and educational resources.	<a href="http://www.ciin.org/">http://www.ciin.org/</a>
<b>The Chemical Sensitivity Foundation</b> (Link to a questionnaire validated by Claudia Miller MD, MS of the University of Texas School of Medicine at San Antonio)	Questionnaire-- <i>The Quick Environmental Exposure and Sensitivity Inventory (QEESI)</i> . PDF download. To help identify individuals with multiple chemical intolerances.	<a href="http://www.chemicalsensitivityfoundation.org/chemical-sensitivity-questionnaire.htm">http://www.chemicalsensitivityfoundation.org/chemical-sensitivity-questionnaire.htm</a>
<b>The Chemical Sensitivity Foundation</b> (Nonprofit corporation whose goal is to raise public awareness about MCS)	Website.	<a href="http://www.chemicalsensitivityfoundation.org/">http://www.chemicalsensitivityfoundation.org/</a>
<b>Independent Living Research Utilization (ILRU)</b> (A national center for information, training, research, and technical assistance in independent living.)	On-line book <i>Understanding and Accommodating People with Multiple Chemical Sensitivity in Independent Living</i> by Pamela Reed Gibson PhD, James Madison University.	<a href="http://www.ilru.org/html/publications/books/MCS.html#help1">http://www.ilru.org/html/publications/books/MCS.html#help1</a>
<b>MDJunction</b> (Social network site for people with health challenges)	Online MCS support group.	<a href="http://www.mdjunction.com/multiple-chemical-sensitivity">http://www.mdjunction.com/multiple-chemical-sensitivity</a>
<b>NeuroTalk</b> (Hosted by PsychCentral, a mental health and psychology network)	Online support group for people with allergies and MCS.	<a href="http://neurotalk.psychcentral.com/">http://neurotalk.psychcentral.com/</a> (Scroll to "Allergies and MCS" under Health Conditions.)
<b>The Ohio State University Extension</b>	Fact Sheet on MCS.	<a href="http://ohioline.osu.edu/cd-fact/pdf/0192.pdf">http://ohioline.osu.edu/cd-fact/pdf/0192.pdf</a>
<b>United States Department of Labor</b>	Website on MCS	<a href="http://www.osha.gov/SLTC/multiplechemicalsensitivities/index.html">http://www.osha.gov/SLTC/multiplechemicalsensitivities/index.html</a>



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## *An Integrative Approach to Environmental Intolerances*

***The information in this handout is for general education. It is not meant to be used by a patient alone. Please work with your health care practitioner to use this information in the best way possible to promote your health.***

References, if needed, can be found in the clinician version of this handout.

This handout was created by by Adam Rindfleisch MPhil, MD, Assistant Professor in Family Medicine and Integrative Medicine Consultant, and Charlene Luchterhand MSSW, Integrative Medicine Education/Research Coordinator, adapted from a handout written for clinicians by Adam Rindfleisch. Both are in the Department of Family Medicine at the University of Wisconsin-Madison School of Medicine and Public Health.

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### **NOTES:**