

**Understanding & Accommodating
People with Multiple Chemical Sensitivity
in Independent Living**

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Independent Living Research Utilization at TIRR

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Chapter 1

An Introduction to MCS and ES

DESCRIPTION

In multiple chemical sensitivity (MCS) a person develops markedly negative reactions to everyday chemical exposures. These include exposures to pesticides in buildings, in gardens, on our food, and on pets; chemical cleaners; petrochemical heating systems; paints; perfumes; industrial emissions; and a myriad of others. We have been conditioned to think of these exposures as being "normal" and inconsequential, but for a growing portion of the population they are not. The condition of MCS develops in two stages induction and triggering. In induction some contact with chemicals causes the person to sensitize to at least one class of chemicals. This contact can be one large chemical exposure such as a chemical spill or a pesticide application, or it can be a low-level, ongoing exposure such as one might experience in a workplace with poor ventilation combined with copy fumes, perfume, and chemical cleaners. After induction the person develops sensitivity to the chemical that was involved in the exposure and to other related chemicals. Thereafter the person will respond with symptoms when exposed to any of this class of chemicals. This is called "triggering." The sensitivities developed are usually more or less permanent, although the kind and intensity of reactions may vary. In what is called the "spreading phenomenon" the sensitivities tend to spread over time to other related chemicals and also to other classes of chemicals. The primary way to avoid reactions once sensitivities have developed is to avoid contact with the triggers. With each new sensitivity this becomes more difficult and the person's access becomes more limited. For this reason one of the major goals in helping people with MCS is to try to limit the spreading by reducing chemical exposures in order to preserve what tolerance the person still has. Unfortunately it is not unusual for people developing MCS to continue to expose themselves to chemicals because at first they do not link their reactions to chemical exposures and/or do not know that repeated exposures can cause a worsening or spreading of their sensitivities.

Although less is known about electrical sensitivities (ES), people who experience them report that they develop in much the same way as MCS. An initiating exposure to an electrical field causes the sensitization, which then sets the person up to experience negative health effects in response to any future contact with electrical fields or radiation. Avoidance of electrical fields is then necessary in order to avoid debilitating health reactions.

What Kinds of Negative Health Reactions Occur?

MCS symptoms can affect any organ system including respiratory, digestive, neurological, endocrine, urinary, cardiovascular, or immune. The health problems experienced from each trigger vary from person to person, but tend to be stable for each person with each trigger. This means that one person may have a constellation of symptoms from petrochemical exposure such as vehicle exhaust that includes headache, confusion, dizziness, and nausea. This constellation occurs each time that person has a petrochemical exposure. There are many symptoms that people can experience from chemical exposure. The five most common symptoms in my research were tiredness/lethargy, difficulty concentrating, muscle aches, memory difficulties, and long-term fatigue. This suggests overlap with chronic fatigue syndrome. Other commonly reported symptoms include digestive problems, joint pain, headache, irritability, tenseness, spacey feelings, insomnia, depression, difficulty making decisions, pressure in the head, rhinitis, sleepiness, eye irritation, coordination problems, dizziness, slow response, chest pain, tingling fingers and toes, nausea, rashes, and hives. Symptoms from electrical sensitivities may include loss of muscle control, noise sensitivity, and other neurological problems.

The health problems triggered by chemicals in people with MCS vary from mild to life threatening, and for some pose very alarming situations. For example one woman in my study gets dangerous blood clots from chemical exposures. An environmental physician described to me a patient whose heart stops in public if she is exposed to chemicals. She has to have someone start it again.

Which Chemicals Cause the Most Problems?

In my research, respondents rated pesticides, formaldehyde, fresh paint, new carpets, diesel exhaust, perfumes, and air fresheners as being the most troublesome chemical exposures. This is congruent with other studies. Other triggers that are rated as being very problematic in various studies include tobacco smoke, fresh asphalt, moth balls, nail polish and remover, phenol, fabric softener, furniture polish, dry cleaning chemicals, hair spray, new vinyl plastic, chlorine bleach, auto exhaust, laundry detergent, natural gas, shampoos and conditioners, and newspaper.

It is also common for people to suffer from inhalant allergies to pollens and molds, or from food allergies. These problems further impair people's functioning. In addition, some people's lives are complicated by sensitivities to electromagnetic frequencies (EMFs), emitted by high-tension wires, transmitters, and other large sources of electricity as well as electrical appliances and other "small" sources found in the home. Although electrical sensitivity is less understood and accepted than MCS, there are some studies now that show that EMFs can alter the permeability of neurons, thereby affecting the levels and circulation of brain chemicals (neurotransmitters). In a number of these studies, EMFs also have been linked to cancer (particularly in children) (Pinsky 1995). I have seen a person with EMF sensitivity lose the ability to walk within seconds of exposure to fluorescent lighting. One moment she was walking fine and the next she appeared to have cerebral palsy simply from entering a building with this type of lighting.

Are These Reactions to Chemicals a New Medical Condition?

Although MCS still is not officially recognized by the medical establishment in the U.S., illness reactions from chemicals, particularly petrochemicals, are not new. Theron Randolph, M.D., thought to be the "Father of Environmental Medicine" was studying allergic reactions to petrochemicals in the 1950s, and called this problem "The Petrochemical Problem." As in the case of most visionaries, he was punished rather than rewarded for his work. He was fired from the University of Chicago School of Medicine for being a "pernicious influence upon students." Randolph's book *An Alternative Approach to Allergies*, written with Ralph Moss, describes his early work, his theories, and the basic tenets of Environmental Medicine. Claudia Miller (1996) believes that we need a paradigm shift in medicine that will take us to an understanding that toxicants are causes of not only MCS, but of a host of other illnesses and disabilities. She believes that this shift in understanding is so substantial as to be comparable to the shift that occurred that ushered in the germ theory of disease. But very little training in toxicology is offered to medical students, and this shift will require a tremendous change in the way that conventional medicine currently understands illness.

CAUSES/HYPOTHESES ABOUT HOW MCS DEVELOPS

Exactly how do chemical exposures alter the body so that the person develops illness reactions to subsequent exposures? Although no one knows for certain, most researchers and physicians who seriously consider the problem believe that chemical exposure is to blame. The following are some of the major theories on exactly how chemical exposures alter the body.

Limbic Kindling/Neural Sensitization

A number of researchers believe that the phenomenon of kindling is involved in the development of MCS as follows: A nerve cell can be isolated and placed in a petri dish and then stimulated either with chemicals or electricity at a level that does not cause it to fire. But if the cell is stimulated repeatedly, it will eventually fire at a level of stimulation below that which would usually be required. In other words it is possible to "kindle" neurological tissue to respond at lower levels of stimulation simply by subjecting it to repeated exposures. Some researchers believe that some people have "kindled" their olfactory system to low levels of chemicals. The olfactory nerve which transmits the sense of smell runs from the nose and connects to the limbic system, the old animal brain that is involved in eating, mood, motivation, and all basic survival functions. Kindling through this nerve or other pathways could render the person sensitive to and affected neurologically by common everyday chemical exposures. Kindling is one of the most respected theories of how the sensitivities develop. Proponents of this theory include Claudia Miller, Iris Bell, and others.

Neurogenic Inflammation

William Meggs has offered another respected theory of how MCS develops that involves the respiratory system. He sees MCS developing much like Reactive Airway Dysfunction (RADS) or Reactive Upper Airway Dysfunction (RUADS) where cells in the airway become damaged from irritants and then generate inflammation. Through neurological connections with other parts of the body (called neurogenic switching) reactions develop in other areas of the body. That is, inflammation at one site induces inflammation at other sites via communication of nerves between the sites. Patients with MCS do have nasal abnormalities upon examination that support this theory (Meggs & Cleveland, 1993).

Other Theories

Other theories on the cause of MCS involve depleted enzyme systems. We know, for example, that particular pesticides are designed specifically to damage enzymes. The organophosphate pesticides (nerve poisons that were used widely in World War II as chemical warfare agents) knock out acetylcholinesterase needed to break down the neurotransmitter acetylcholine. When too much acetylcholine builds up between the nerve cells bugs die of convulsions. Unfortunately, the human nervous system contains many of the same neurochemicals as bugs, including acetylcholinesterase. People can suffer a number of severe problems from cholinesterase poisoning including nausea, vomiting, abdominal cramps, frequent and/or involuntary defecation and urination, wheezing, visual disturbance, weakness, fatigue, and muscle cramping or twitching. People can suffer delayed neurological damage that may include disturbances in sensory experience, motor function, speech, sleep, and emotional stability (Sherman, 1995). Some people have also developed MCS following an organo-phosphate pesticide exposure. The mechanism of how organophosphate exposure causes chemical sensitivities is unclear, but probably involves residual brain damage of some sort.

Albert Donnay (1999) of MCS Referral and Resources has proposed that carbon monoxide exposure is a cause of MCS. There are historical descriptions of ill health that resemble MCS. This theory has prompted some physicians to experiment with oxygen treatments, which are useful in acute carbon monoxide poisoning, in patients with MCS.

A large number of chemicals, particularly solvents, are known to cause neurological damage. Painter's syndrome is a condition that afflicts old painters who have a long history of exposure to paints and solvents. Neurological examinations of workers exposed to solvents reveal a variety of neurological abnormalities including problems with memory, attention and learning, as well as psychological symptoms. Lisa Morrow at the University of Pittsburgh and colleagues have published a number of studies in this area (Morrow et al., 1990). Exposures to solvents have also preceded the development of MCS in some people.

Because the problem of electrical sensitivities has not been researched as much as MCS, theories on how it develops are lacking. It has also received less attention from writers and health practitioners.

PREVALENCE

The earliest estimation of how many people have MCS came from the National Academy of Sciences, which suggested that 15% of the population has sensitivities to common chemicals. Meggs and colleagues (1996) did a household population study and found that about one third of the population reported having sensitivities to chemicals. Chemical sensitivity affected persons of all ages, incomes, races, and educational levels. A little under 4% reported becoming ill every day from sensitivities. Two state health department studies have found similar results. In New Mexico, 16% of people reported being sensitive to chemicals, 2% had been diagnosed as having MCS, and sensitivities had caused 2% to lose a job or career. In California, almost 16% of adults were chemically sensitive and 6.3% had been diagnosed with MCS or environmental illness (Kreutzer, 1999). If Meggs and colleagues are correct that 4% of the U.S. population is becoming ill every day from chemicals, this means that over 11 million people have moderate to severe MCS. MCS currently is not included in disability databases and will add substantially to the commonly cited figures of 43 to 48 million Americans with disabilities (NIDRR, 1999).

Consumer and volunteer samples to date are all approximately 80% women. But, population studies such as the Meggs study find a smaller majority for women with about a quarter of men and over a third of women reporting illness from chemicals. We don't really understand why more women than men may be affected, but there are several suggestions.

Women are more susceptible to auto-antibody and autoimmune illness and chemicals induce auto-antibodies. Women have less of an enzyme that detoxifies both alcohol and chemicals called alcohol dehydrogenase (Freeza et al, 1990). Women are also smaller on average than men, have a higher respiration rate, and may be more vulnerable to hormone-disrupting chemicals (many toxics are estrogen disrupters.)

MCS is not limited to North America. Researchers have identified chemical sensitivity in several Northern European countries and in Greece (Ashford et al., 1995).

Electrical sensitivities were addressed by the California Department of Health Services in the 1998 California Adult Tobacco Survey and found to affect 3.3% of 2,072 adults surveyed (Levallois et al., 2000). But because this research was conducted via telephone, and people with electrical sensitivities often cannot use the telephone, it probably underestimates the numbers. Even so, the 3.3% extrapolates to 8 million Americans having ES.

CULTURAL RESPONSE

Our cultural response to MCS has been almost entirely negative. People with this primarily invisible disability have been ignored, de-legitimized, dropped as friends, discriminated against in the workplace, fired from their jobs, and excluded from housing and medical care. Although there are some agencies that either recognize MCS or are attempting to incorporate it to some extent into their programs, for the most part the problem has been ignored. There has been no concerted attempt on the part of the medical community to learn about MCS. Although practitioners of environmental medicine see Theron Randolph as a mentor and deal primarily with MCS patients in their practices, they too suffer discrimination from the greater medical community because of this.

My framework for understanding MCS after nine years of research is this: MCS is an illness that is caused by industrialism, it is an indictment of industrial culture because it directly points to chemicals as a cause of disability, and it is totally incongruent with industrial culture. We are a culture that does "risk assessment" of each of our chemicals allowing a certain number of people to get sick or die from exposure to each chemical. While the EPA continues to compile lists of cancer causing agents, the field of health psychology continues to look for the "cancer personality" that supposedly renders some persons more psychologically prone to the development of cancer. We are experts at ignoring the obvious. While babies on the U.S. - Mexico border are born without brains, our industries continue to dump wastes into the air and water of that geographic region. Our institutions are created out of the same industrial paradigm that allows this contamination, and are therefore not only not positioned to respond in any constructive way, but are in many cases set up to deny and distort the reality of chemical-induced disability. This cultural set-up makes for personal struggles in a number of venues.

HOW TO HELP

- Understand the person's need to meet in a very clean environment. Try to provide a setting free of fresh paint, pesticides, smoke, perfume, forced air petrochemical heat, chemical cleaners, and other toxics. Ask the person exactly what incitants she or he needs to avoid. As an accommodation, it may be necessary to speak by phone or go to the person's home if getting to the center and surviving the environment there will be a hardship. If you go to the home of a person with MCS please follow any procedures requested by the person regarding what to avoid on your person, despite how odd the request might sound to you. The person might request no fragrance or hair spray, no freshly dry-cleaned clothes, no mothball fumes on clothes, no exposure to cigarette smoke that can be carried on clothes, or some other procedure to avoid what we call secondary exposures. Your clothing and hair pick up smoke, perfume, and other chemicals when you encounter them, and someone who is extremely sensitive can react to you because you are carrying these chemical fumes.
- Understand that if the person has electrical sensitivities, he or she will have problems with a number of devices that are probably in your agency including battery re-chargers, oxygen concentrators, air filters, any electrical monitoring equipment, fluorescent lighting, and computers. You may have to turn off lights and unplug some equipment in order for these people to have access to your facility.
- Provide an accepting and supporting attitude. By the time the person makes it to your agency, he or she has endured enough rejection for a lifetime. Try to eliminate any

attitude you might have about MCS not being a 'real' disability. (This is usually fairly easy once you hear about the person's life experiences.)

- Learn as much as you can about MCS and what people with MCS say about having it. They are the best source of information. The rest of this book is devoted to helping you understand their personal struggles with this disability.
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Chapter 2

The Health Care Challenge in MCS

Obtaining medical care for the person with MCS can be a severe struggle for a number of reasons. Most medical, psychiatric, and rehabilitation facilities are inaccessible to people with this disability and health practitioners are usually uninformed about the condition. The conventional medical community has not recognized MCS, and has even attempted to censure and intimidate those physicians who do attempt to work with people with this problem. There is no training regarding MCS in medical schools, therefore, most physicians are unfamiliar with it. There is, however, a branch of medicine that does treat MCS. The work of Theron Randolph (mentioned in the previous section) evolved the field of Environmental Medicine. Randolph did groundbreaking clinical work and found that many of his patients were allergic/sensitive to heating fuels, gas cooking emissions, and other environmental pollutants. He was then able to train other physicians and is the mentor of many of the environmental physicians practicing today. Some people with MCS seek help from these practitioners, although they are sparsely located and can be very expensive. Many with MCS report great benefit from this approach to treatment.

The field of environmental medicine espouses several basic concepts that can be helpful if you work with people with MCS or electrical sensitivities. Chemical sensitivity is seen as developing in two stages that of induction and then triggering. In induction, one large chemical exposure, or perhaps an ongoing more moderate one can damage the nervous system and/or immune system causing the person to become sensitized to the chemical in question. Persons with electrical sensitivities report that the condition seems to be initiated in much the same way - with a significant exposure to electromagnetic radiation or fields. Further exposure to that substance then triggers symptoms (the triggering phase). If a person with MCS is exposed to one substance at a time it is fairly easy to determine cause and effect. But if the person has multiple exposures, simultaneously or back to back (which is often the case), it is very difficult to pinpoint what is causing the reaction and the person just feels bad continually. This is called masking. If a person lives in a house that is not safe for him or her, there will be continual symptoms, but their relation to the house may not be clear. The way to unmask is to stop the exposures. The person whose home is in question can go to a safer locale for 4-5 days. Upon return to the home, the symptomatic reaction is then likely to be very dramatic if the home is not safe. Although this is uncomfortable, it is one way of identifying unsafe triggers. Because MCS tends to demonstrate the spreading phenomenon where sensitivities develop to other chemicals in the family of the original sensitizer and then to unrelated exposures, the person is faced with a repeated need to sort out the sources of his or her adverse reactions.

Another important concept of environmental medicine is called total load. The total load concept says that your body can only tolerate so many exposures before it reaches its limit, "filling up" with too many irritants. Patients of environmental medicine are urged to keep their exposures to chemicals, allergic foods, electromagnetic fields, microwaves, molds, and other inhalant allergens to a minimum in order to minimize stress on the body. Avoiding exposures is seen as being the best method of improving health. Patients are encouraged to clean up their homes and to create a special "oasis" in their bedroom where their exposures will be as minimal as possible in order to have a place to clear out and heal after receiving outside exposures. The oasis should be sparsely furnished with no carpeting, pesticides, petrochemical heat, fresh paint, mold, dust, or books, and perhaps even no clothing to minimize dust. Ideally, bedding should be all natural, but many people with MCS have been able to tolerate aired out camping mattresses. People with electrical sensitivities are urged to avoid electromagnetic fields and shield themselves from those that cannot be eliminated (e.g., many shield their computers). Their bedrooms should have no fluorescent lighting, computers, clocks, or other electrical appliances. When going out in public some people with ES wear ear protectors or even helmets or aluminum foil on their heads to protect against magnetic fields.

Practitioners of environmental medicine use testing techniques that conventional physicians consider controversial. In provocation/neutralization testing the person is challenged with very small amounts of various triggers (foods, chemicals, molds) either subcutaneously (under the skin) or sublingually (under the tongue), and symptoms are elicited right in the medical office. A diluted dose of the same antigen is then used to neutralize the reaction. People who have fairly stable reactions (that is the amounts of antigen needed to neutralize do not change often) are seen as good candidates for P/N testing and neutralization.

Some drawbacks of environmental medicine are that these practitioners are expensive and sparsely located. Note that even these practitioners may not use the diagnosis of MCS or ES. Because of the lack of general acceptance by the insurance industry for the conditions, they may list other diagnoses such as asthma or porphyria, in order to obtain reimbursement. They may also want to avoid controversy due to the harassment that is often directed toward physicians who work with people with MCS and electrical sensitivities.

Most people do not have an environmental medicine practitioner easily accessible to them and must primarily depend on conventional doctors. Finding one who will seriously consider chemical sensitivities is not an easy task. Even if a person does locate a cooperative practitioner, often the office is inaccessible due to the presence of petrochemical heating systems, pesticide use, perfumes on medical personnel, unsafe building materials, and, for those with electrical sensitivities, cellular phones, fluorescent lighting, and electrical equipment. Consequently, people not only lack treatment for their sensitivities, but are forced to neglect routine and preventive care that others in an industrial culture take for granted. This includes routine check-ups, mammograms and dental cleanings. Consequently people with MCS are at risk for other health problems that could be better treated if detected early. In addition to the inaccessible office, chemically sensitive people have the realistic fear of having adverse reactions to medical treatments such as anesthetics, medications, dyes used in x-ray testing, and others. People therefore tend to avoid dental procedures, elective surgeries, and any invasive testing. One woman in my study chose to suffer for two years with an abscessed tooth rather than be exposed to anesthetics. Others told me that they went without anesthetics for procedures that really need them such as having cysts removed, having root canals and teeth pulled, and invasive tests.

People with electrical sensitivities avoid medical treatment because they also are likely to be so harmed by the exposures (in this case to the electrical equipment) that the visit isn't worth the

risk. In addition, their symptoms may be altered completely if they are observed while exposed to electrical fields. So people with MCS or ES are having a hard time getting any medical care, even that unrelated to their sensitivities.

The flip side of the lack of care, however, is often a desperate search by people with MCS and ES for answers and treatment for their sensitivities. People experiment with both conventional and alternative therapies. Many deplete their finances and even incur debt paying for treatments that are not helpful. The 917 people in my recent treatment study had seen an average of twelve health providers, but described only three as helpful. They had spent an average of \$51,000 on total health care since their illness began, \$7,000 of it in the past year. This amounted to over one-third of their annual personal income going to health care costs.

Respondents had used an average of over 30 treatments. People who were more disabled had tried more treatments than those more mildly affected. People tended to use about 10 nutritional supplements, several environmental medicine techniques such as creating an oasis or safe living space, and 2 or 3 different therapies in each of the categories of holistic therapies, body therapies, and prescription items. Respondents saw creating a chemical-free living space, chemical avoidance, and prayer as being the most effective interventions. Both creating a chemical free living space and chemical avoidance were rated by 95% of people as helpful. Other therapies rated as highly effective included rotation diet, air filters to reduce exposures, personal oxygen to cope with exposures, acidophilus supplements, acupressure, touch for health, reflexology, moving to a safer location, and meditation (Gibson, Elms, & Ruding, 2001).

Many people with MCS experience harm from medical care due to unnecessary, inappropriate, or delayed medical treatments. People in my research were given inappropriate drugs, had long delays in diagnosis, were treated for the wrong conditions, were given unnecessary invasive medical tests, had one or more unnecessary surgeries, and were even inappropriately given shock treatments.

Mental health practitioners were not any more helpful. Although 70% of my survey participants saw mental health providers, most of these providers were reportedly not helpful. To the contrary they often caused harm by ignoring patients' chemical sensitivities, inaccurately giving psychiatric labels, drugging people, or suggesting psychiatric hospitalization. And 15% of those who saw mental health providers were actually hospitalized. They suffered further harm from exposures to chemicals and EMFs in the institutions and had to deal with the loss of life control imposed by the psychiatric system. People with electrical sensitivities may have an especially difficult time in psychiatric institutions given the stereotype of the mentally ill person complaining about radio waves. Persons with ES will likely be ignored when they ask their doctors to turn off cell phones, motors, and other equipment, as will people with MCS who ask not to be exposed to perfume, cigarette smoke, pesticides, and cleaning products.

Finally the person with MCS or ES has to face that there is no real cure for their sensitivities. Although some treatments are rated fairly highly, they usually only help reduce but not eliminate symptoms. The treatment studies suggest that most treatments actually help no more than about 25% of people and cause harm to others. That is, there is no magic bullet for MCS. Some treatments are in fact consistently rated as being more harmful than helpful by people with MCS. Psychotropic drugs such as anti-depressants as well as anti-anxiety medications like valium are rated poorly. In general the non-toxic, less intrusive therapies are rated better than any chemical therapies or very expensive "designer" nutrients. But people should consult the studies, talk to their doctors, and make their own decisions as to what to try. Repeated unsuccessful interventions can be a costly and demoralizing experience. As hard as it may seem, one should always keep in

mind that a new therapy may not work. This is not always easy when a situation seems desperate, as is often the case. Consequently, I've seen many people go into debt to try new and expensive treatments, only to become sicker from the process and be financially drained besides.

People with MCS have different philosophies as to whether sensitivities are permanent or not. Some believe that there is a treatment out there for them and they just need to find it. Others believe that there is no real cure for MCS, and that simply trying every therapy that comes along is a waste of time, energy, and money. This group tends to believe that one has to accept MCS as a long-term disability and learn to live with it. This doesn't mean that they give up or stop judiciously trying to improve. But they believe that the desperate search for a cure is a distraction from adjusting to having a disability. Accordingly, by the time some people come to the Center for Independent Living for help, their enthusiasm for medical treatment may have waned. As their advocate you will have to respect the persons' right to choose what treatments to pursue.

HOW TO HELP

- Collect and share names of any supportive physicians who have helped other people with MCS or electrical sensitivities. If people want to find a practitioner of Environmental Medicine they can contact the American Academy of Environmental Medicine for a practitioner near them. American Academy of Environmental Medicine (AAEM), American Financial Center, 7701 East Kellogg, Suite 625, Wichita, Kansas 67207. Phone: 316-684-5500. Web site: www.aaem.com
- The Chemical Injury Information Network (CIIN) can provide a list of physicians that work with people with MCS. The list includes practitioners of Occupational Medicine, Immunotoxicology, Environmental Medicine, and other specialties. CIIN can be contacted at PO Box 301, White Sulphur Springs, MT 59645. Phone: 406-547-2255. E-mail: chemicalinjury@ciin.org. Web site: www.ciin.org

Books on Environmental Medicine

The basic tenets of Environmental Medicine are explained in T. G. Randolph, and R. W. Moss. 1982. *An Alternative Approach to Allergies*. New York: Harper & Row. The book describes Randolph's work with chemically sensitive patients as early as the 1950s and includes many case studies.

- Books by Sherry Rogers, M.D.: From Prestige Publishing, P.O. Box 3161, Syracuse, NY 13220:
- Rogers, S. 1986. *The EI Syndrome*. Syracuse, NY: Prestige Publishing.
- Rogers, S. 1990. *Tired or Toxic?* Syracuse, NY: Prestige Publishing.
- From Phillips Publishing, Inc., 7811 Montrose Road, Potomac, MD 20854. 1-800-301-8970.
- Rogers, S. 1997. *Are Chemicals Making Me Sick? A Primer on Chemical Sensitivity*.
- Rogers, S. 1997. *Dr. Rogers' Solutions to Common Medical Problems*.

- Rogers, S. 1997. *Why Am I So Tired? Dr. Rogers' 60-Day Plan to Boost Your Energy*. From SK Publishing, P.O. Box 40104, Sarasota, FL 34242. Phone: 1-800- 846-ONUS:
- Rogers, S. 1994. *The Scientific Basis for Selected Environmental Medicine Techniques*.
- Rogers, S. 1997. *Depression: Cured at Last*.

Detoxification

The following book by an environmental physician is a comprehensive guide to detoxification:

- Krohn, J., F. A. Taylor, and J. Prosser. 1996. *The Whole Way to Natural Detoxification*. Point Roberts, WA: Hartley & Marks.
- Share the following 4 treatment studies.

Gibson, P. R. (2000). Treatment data reported in chapters 6 and 7 of *Multiple chemical sensitivity: A survival guide*. Oakland, CA: New Harbinger Publications.

Gibson, P. R., Elms, A., & Ruding, L. (2001). *Self-reported treatment efficacy in 917 persons with multiple chemical sensitivity*. Paper presented at the Chemical Injury Information Network MCS Conference, August 13-15, Sante Fe, NM.

Johnson, A. 1996-1998. *MCS Information Exchange Newsletter*. November 8, 1996; March 20, 1997; September 19, 1997; February 13, 1998.

Brunswick, ME: MCS Information Exchange. MCS Information Exchange, 2 Oakland Street, Brunswick, Maine 04011.

Leroy, J., T. H. Davis, and L. A. Jason. 1996. *Treatment Efficacy: A Survey of 305 MCS Patients*. *The CFIDS Chronicle*: Winter, 52-53.

Chapter 3

THE EMPLOYMENT CHALLENGE IN MCS

Another great stressor in MCS is that of work. In my life disruption study, less than a third of the MCS participants were still working outside of the home. Sometimes it was the workplace that caused the person to develop MCS to begin with. Over half of those who reported an initial known exposure that damaged their health reported that it occurred in the work environment. When work causes the MCS, the situation is made worse by the fact that the worker is faced with compensation and liability issues at a time when their personal resources are at a very low ebb.

HOLDING ONTO EMPLOYMENT FOR THOSE WITH MCS

Even if work was not the initiating exposure, the person may find that s/he now is made sick by exposures to any number of workplace toxics including pesticides, new carpet, paint, copy fumes, fragrances on co-workers, petrochemical heat, or electromagnetic frequencies. By the time a person comes to the Center for Independent Living for help, his or her employment situation is most likely at crisis level. When a person asks for workplace accommodations, there is often resistance from both co-workers and superiors. If colleagues are uneducated about MCS or get their information from misguided sources, they are unlikely to be sympathetic or helpful. Unfortunately, people with MCS have been harassed in the workplace, including the extreme measure of persons intentionally exposing them to toxics. Persons in these kinds of situations are therefore likely to be suffering considerable upset around the issue of work.

If the person has continued to try to work without accommodations, he or she may have deteriorated in health, and, as a result, may now no longer be able to work at all. People who are the primary income earners in families may be most at risk for this because they feel a responsibility to provide for their loved ones. Employment should be preserved whenever possible in order for persons to maintain their income, benefits, work-related self-esteem, contacts with other people, and sense of being productive. But for most people with MCS, this cannot be accomplished without accommodations. Being familiar with disabilities in general and the ADA, you are in a position to help the person write a Request for Reasonable Accommodation. The request for accommodations should be in writing and accompanied by a physician's letter if possible. In this legal document the person can request the workplace adjustments that will limit workplace exposures to toxics and allow the person to perform her or his work. It will also hopefully halt or slow the spreading phenomenon and help maintain the worker's level of health.

Some workplace changes, such as using an air cleaner, can be done by the individual without help from the workplace. People can also unplug or turn off equipment and lighting in their personal workspace if they emit electric or magnetic fields that trigger their symptoms. Changes that can be requested from the workplace include the use of less toxic cleaners, a reduction in fragrance on co-workers, less toxic pest management, and notice regarding any painting or construction. Changing airflow and heating is more difficult although it is certainly reasonable to ask that HVAC systems be cleaned and maintained properly. If the workspace is taking in toxicants from other parts of the building, or the air quality is poor for other reasons, the person may have to ask to relocate her or his office.

Accommodations are more difficult to obtain for common areas than for a personal workspace. For example, it may be difficult to talk employers into discontinuing the use of "air fresheners" in the bathrooms. The employee will likely have to do the research and suggest product changes such as using baking soda or fragrance-free kitty litter, changed on a regular basis. Citrus-based air fresheners are another possibility but are not tolerated by most people with MCS.

People should probably be judicious, asking for only what they really need. An employer does not have to make an accommodation that imposes an "undue hardship" on the operation of the business or organization. Undue hardship means "significant difficulty or expense" when taking into account (on a case-by-case basis) the structure and resources of the institution or workplace.

Employers are able to make many MCS accommodations with little expense. Limiting smoke and perfume in the workplace, using less toxic air fresheners or paints, providing an air cleaner for employees, and using less toxic bug control are all reasonable strategies for reducing workplace

toxics. The employee may want to use the booklet *Multiple Chemical Sensitivities at Work: A Training Workbook for Working People* by the Labor Institute (1993) as a workbook for possible accommodations for those with MCS. Some suggestions for accommodations are listed below. If the employee does receive some cooperation, she or he then needs to stay abreast of plans for remodeling, repairs, and pest control so that she or he can suggest less toxic alternatives and/or avoid the toxic exposures that may be associated with these activities.

Potential Workplace Accommodations for MCS:

1. Provide a workable window that opens for ventilation.
2. Reduce fragrance on co-workers.
3. Replace toxic pesticides with less toxic alternatives, such as using flyswatters or using boric acid for ants and roaches.
4. Initiate flexible work hours that allow the employee to leave during potential chemical exposures (e.g., painting) and/or to work during off-hours to avoid photocopy and other office fumes, or rush hour traffic.
5. Provide notification of impending pesticing, painting, and construction.
6. Use nontoxic fume-absorbing substances, fans, or windows instead of chemical "air freshener" in bathrooms.
7. Relocate the employee to a safer part of the building.
8. Provide an air cleaner for the employee's work area.
9. Vent the photocopy machine to outside the building.
10. Use unscented less toxic cleaners as replacements for ammonia, solvent, phenol, or chlorine-based solutions.
11. Delegate errands to toxic areas, such as photocopying and other small nonessential tasks, to an employee who does not have chemical sensitivities.
12. Minimize the amount of time the employee spends under fluorescent lights or in the vicinity of transformers, electric cables, computers, or other electromagnetic field sources that trigger symptoms.

When The Person With MCS Can No Longer Work

Sadly, many persons with MCS fail in their attempt to maintain employment. Three-quarters of people in my life impact study had lost or had to quit their jobs because of their MCS. In fact only 7% were working in conditions that they considered safe for their health at the time of the study. People with electrical sensitivities, in particular, may be unable to alter a workplace enough for their safety given the widespread presence of EMF-emitting technology.

Many people with MCS have become so sensitive to chemicals that they can no longer work even with accommodations, or they may be unable to work in their chosen field because of the toxic nature of the work. Hairdressers, chemists, painters, and exterminators who develop MCS probably cannot continue or resume their careers, even with accommodations.

Helping the person with MCS with alternative employment or compensation is another big challenge for advocates. Some people are able to seek alternative employment in a safe workplace environment or make some income from a small home-based business, but many are unable to work at all. If work is lost, the personal consequences are often severe. Loss of work in combination with escalating housing and medical costs easily leads to financial ruin. As a result of their MCS, people in my life impact study reported that they had lost almost \$18,000 per year of their incomes. They now earned on average about \$12,000, much of which was disability compensation. They had also lost their health insurance and retirement benefits.

The loss of work deprives the person of their former role and contact with co-workers, and forces an isolation that can lead to depression and despair. One nurse in my study mourned that her disability had robbed her of her opportunity to help others even though she had the training and the empathy to do so. If the workplace extrudes rather than accommodates the worker, the person disappears into a hidden group of people with invisible disabilities and business goes on as usual.

GETTING COMPENSATION FOR MCS

As an independent living advocate, you are in an excellent position to understand private and public disability benefits. But unfortunately, obtaining benefits for MCS is extremely difficult. Even if an employee has private disability insurance, conditions resembling MCS may be excluded. In addition, some companies discriminate between physical and mental conditions, limiting benefits for mental conditions to two years duration. So even if the employee does succeed in obtaining private disability compensation, if the company can get the employee's condition labeled as a mental one (either initially or after a period of compensation), then benefits can be of limited duration. An additional obstacle to obtaining benefits is private insurers' use of "expert" witnesses who they hire to testify for employers against people applying for MCS compensation.

Social Security Disability Benefits are also difficult to obtain. The person with MCS is usually faced with the task of convincing people who know nothing about MCS that they are unable to engage in gainful employment anywhere. Examiners have a difficult time understanding why the person cannot "perform other work in the national economy." People must be able to demonstrate or explain that they a) become debilitated by common chemical exposures, and b) have no control over these exposures that depend upon other people's behavior. People in my studies reported using creative strategies to convince examiners and judges of their problem such as videotaping themselves during a reaction or having friends testify as to their health and behavior both before and after developing MCS. Since examiners must use "all relevant medical and non-medical evidence," these strategies are acceptable. SSA's listing of impairments includes over 150 categories presumed to meet the severity test for acquiring benefits. MCS is not on it and, being unlisted, must be the "medical equivalent" of one of the listings. Criteria for mental impairments are more subjective and focus more on subjective evaluation of the person's functional limitations than those for physical impairments, which are supposed to be documented more by medical fact. Although there are conditions that must be assessed by functional limitation, e.g., musculoskeletal conditions, awards for these conditions are infrequent. MCS falls into the category of impairment that is difficult to document by medical fact, and therefore the person **MUST** prove functional limitation.

Half of the people in my initial study had applied for disability benefits. Of the 151 who applied, 104 described the process to us (75 women and 29 men). Of these 104 people, 51 had filed once, 22 twice, 28 three or more times. Fifty-nine participants had been awarded disability benefits, 13 were denied at the time of the study, cases for 31 individuals were still pending, and one response was unclear. Of the 59 people who received disability income, 29 were awarded benefits on the first petition. It cost people an average of \$2,060 to go through the process, took an average of twenty-three months to complete, and resulted in an average award of \$12,702. Because MCS is so poorly received, people used a number of labels in their application process: MCS-related labels such as multiple chemical sensitivity, environmental illness, toxic encephalopathy, and sick building syndrome were used by 48 people; other diagnoses by 23 (even though MCS was their primary health problem); and a combination of MCS and other labels by 29 applicants. Other labels combined with MCS included psychiatric problems (n=11), respiratory illness (n=10),

musculoskeletal dysfunction (n=7), chronic fatigue immunodeficiency syndrome (CFIDS) (n=5), immune disorders (n=4), circulatory problems (n=3), gastrointestinal disorders (n=3), and others (n=17). Medical evidence used for documentation included blood work, brain scans, allergy tests, and neuropsychological examinations, among others.

The 60 people who used attorneys had to search diligently for someone educated about MCS. One woman approached over twenty lawyers, none of whom would accept her case. People were granted disability under the following labels:

<u>Label</u>	<u>Number</u>
MCS Related*	44
Psychiatric**	27
Chronic Fatigue Immunodeficiency Syndrome	7
Musculoskeletal	3
Circulatory	2
Immune Related	2
Respiratory	1
GI	0
Did Not Know	9
Other	10

* Includes labels such as multiple chemical sensitivity, environmental illness, toxic encephalopathy, sick building syndrome, sensitivity to fumes, multiple allergies, chemical allergy, multiple hypersensitivities, etc.

** Psychiatric labels include: depression (n=7), posttraumatic stress disorder (n=4), conversion disorder (n=2), schizophrenia (n=2), somatoform disorder (n=2), anxiety disorder (n=2), affective disorder (n=2), schizoid personality disorder (n=1), dementia (n=1), "emotional" (n = 1), global assessment of functioning scale = 50 (n=1), and unspecified psychiatric (n=2).

Psychiatric labels can be inaccurately and inappropriately assigned for a person even if their personal physician supplies only a physically based diagnosis. For example, 27 people in my study were granted disability benefits for psychiatric reasons even though only seventeen people had filed their petition with a psychiatric diagnosis. Even if none of the applicant's personal health providers believe the applicant has a psychiatric diagnosis, an SSA-chosen expert's psychiatric designation can be used for disability eligibility. For example, one woman filed for disability for chronic fatigue syndrome (CFS) and was granted disability for paranoid schizophrenia. Because of financial desperation, some people reluctantly allowed the use of psychiatric diagnoses in order to receive benefits necessary for them to survive.

Physician documentation may be the most crucial component of the application process for those with MCS. The documentation needs to be from physicians who are knowledgeable about and supportive of chemical sensitivity. Physician statements should include information about the condition in general, and contain detailed information that documents that the person in question meets the requirements under Social Security of being unable to engage in gainful employment. The examiners and judges are supposed to give greater weight to the opinions of the person's own physician, to physicians with long relationships with the person, and to physicians with special training in the area in question rather than to opinions of consultants who have reviewed the person's medical records or only seen the person once. However, having actually seen the person also gives more weight to a physician's testimony. Therefore agreeing to see a hostile independent

medical examiner (IME) hired by industry may be a poor decision on the part of the applicant because this will give more to the IME's testimony.

HOW TO HELP

- Maintain a list of physicians knowledgeable about MCS who will help persons in need of disability documentation for accommodation requests or for disability compensation applications.
- Help people to think critically about remunerative work they may be able to perform.
- Offer to provide educational resources and training about MCS so workplaces can make better decisions.
- Consider providing employment to someone with MCS in order to have an expert resource for persons requesting advocacy.
- Follow court related decisions about workplace accommodations for MCS in order to be aware of what courts are interpreting as "reasonable accommodation."
- Help the person develop stress-management mechanisms to help them through the long and difficult period of acquiring disability compensation.
- For more in-depth suggestions on making workplace accommodations, go to the Job Accommodation Network's Web site at <http://www.jan.wvu.edu/media/MCS.html>.
- Have the following workbook on hand to help people brainstorm about strategies:

Multiple Chemical Sensitivities at Work: A Training Workbook for Working People. 1993. New York: The Labor Institute. Available from The APEX Press, Publications Office, P.O. Box 337, Croton-On-Hudson, NY 10520. Also available is a half-hour videotape "MCS: An Emerging Occupational Hazard." Both are also available from ECHO, P.O. Box 0119, Hebron, CT 06248-1119. Phone/Fax: 860-228-2693.

Chapter 4

THE HOUSING CHALLENGE IN MCS

CURRENT HOUSING CONDITIONS FOR THOSE WITH MCS

Housing may be the single most crucial element in survival and possible improvement for someone with MCS. Yet it is almost impossible for people with MCS to find places to live that are truly safe for them. Housing may be their most difficult challenge, a challenge greater even than for people with other disabilities. Toxic chemicals such as formaldehyde, and those found in glues, paints, new carpet, and pesticides are commonplace in construction of all types. In addition, it is impossible to control what occurs beyond one's property lines. City dwellers are

subject to industrial emissions, vehicle exhausts, toxics used by neighbors such as lawn chemicals, and a myriad of other poisons. Rural dwellers are exposed to farm chemicals that include pesticides, herbicides and chemical fertilizers. All traditional pesticides and herbicides are extremely toxic. In fact, some insecticides were first mass-produced as chemical warfare agents for World War II. The use of pesticides is now so widespread it is almost impossible to avoid exposure to them. We use these chemicals on our pets, our food, our land, and ourselves. Between the widespread occurrence of toxic building contaminants and the tremendous cost of home cleanup, few with MCS actually live in truly safe conditions. Those who do may have spent their life savings to redo their homes, or may be living beyond their means to afford a home that is isolated enough to avoid neighbors' toxins.

It is imperative for the person with MCS to create the cleanest possible living space. This cleanup requires learning about everyday toxics and safer alternatives, and demands at least some financial investment. Respondents in my treatment study had spent an average of \$57,000 to replace toxic carpeting and furniture, buy water and air purifiers, or move if their home could not be cleaned up. A few with enough money built homes out of safer materials, but this requires considerable investment of time, money, and energy. Those who have built their own homes report that it is necessary to supervise every aspect of the project, including inspecting every item that arrives for use. One must be on guard for contractors substituting less safe items and materials not being as represented. If someone has the resources to be able to build a safe home, there are a number of good resources and consultants to help with the process.

Even though it is important for every person with MCS to try to create as safe and chemical free living space as possible, only about 40% of people in my life impact study said that they lived in safe homes. A slightly larger group (44%) said that their homes should be better. And 16% said that their homes were not safe. The Environmental Health Coalition of Western Massachusetts' housing committee found that three quarters of the 49 people with MCS in their housing study had had to stay in places that made them sick at some point. Almost half had spent more than they could afford to stay in safe housing. And over half had encountered landlords who were unwilling to accommodate their MCS.

Some people in both studies were unable to tolerate any traditional housing due to chemicals used in construction, and contaminants left by previous tenants/occupants, and, as a result had lived in substandard and unusual conditions. The Environmental Health Coalition of Western Massachusetts' housing committee found that 10% were homeless at the time of the survey and another 10% lived in situations such as campers, trailers and cabins (Wachsler, 2001). People with lower incomes were most likely not to have adequate housing, with almost half of those with incomes under \$12,000 having substandard or no housing. Two-thirds of my respondents had lived in unusual conditions such as in RVs, tents, cars, or porches at some point since developing MCS. One respondent in my research had lived in her horse trailer for a year. The following woman's experience is typical of the nomadic lifestyle that some people are forced to adopt:

I have slept outside summer and winter for about 12 years now - including 30 below - windows open - bundled up and using soapstone rocks to keep bed warm - unheated little building. Have slept under homemade mosquito netting under a pavilion - anchored around chairs for weeks - slept in borrowed tent, borrowed trailer - borrowed camper - have slept on relatives' and friends' porches outside for weeks when roadwork done at my house - have commuted for essentials.

I believe that MCS is an important and unrecognized contributor to homelessness. As people disappear from a visible lifestyle and adopt coping mechanisms such as living on porches and in RVs, they approach the divide between those with and without homes. When they slide over that divide there is no record of it and they disappear. Some go to live in tent communities in the Southwest, but for others it is even worse than that. One woman in my most current study sent me a drawing of her "home," which consists of a wire mesh cage to sleep in. Because she must sleep outdoors, she has constructed this cage to protect herself from dogs and wild animals. Her home is literally a five-foot cage. Gail McCormick, in her book, *Multiple Chemical Sensitivity: Narratives of Coping*, interviewed a young woman who must sleep outside under a tarp because of her inability to tolerate indoor environments. She lives a nomadic lifestyle moving from place to place in search of safe conditions. Her mother often travels and camps with her, but at times herself needs a break from the rugged lifestyle. Her daughter sleeps outside in the woods while she rents a hotel room. But if there is a wind that blows the tarp down, her mother must get up at night, drive to where her daughter is sleeping, and cover her up again with her tarp because her daughter is too weak from chronic fatigue to get up and retrieve her own tarp. Some would say that these are extreme living conditions even for the homeless. Yet these struggles are all too frequent among people with MCS and remain virtually invisible to the mainstream culture.

One Alternative Model: Ecology House

Ecology House is an eleven-unit MCS apartment complex in San Rafael, California that, although not perfect in terms of its urban location, is a controlled MCS living space. The arrangement allows people with MCS to actually live in community with others. People have different opinions as to whether funding for people with disabilities should be spent on segregated housing for people with the same disability. But Connie Barker, a resident of Ecology House, described the benefits of living there in preventing total isolation of the residents in the IL NET teleconference on MCS (2/20/02). Connie phoned in and described no longer being the "mad woman in her parents' attic," but rather being able to have some sense of community with people who understand her disability. People with MCS spend a lot of time explaining themselves to others and usually are still not understood. Living where other people understand your needs saves valuable energy and time that can be put into creative and constructive pursuits. Although there were a number of problems when Ecology House was built such as difficulty with materials that were supposed to be inert but actually outgassed significantly, it is now working well. Connie reports that there are three or four people there who have gotten substantially better as a result of living there. There is a long national waiting list of people interested in becoming residents.

Connie explained that building with safer materials for MCS housing is only half the battle. Property management is equally important. At Ecology House residents are notified by the building manager no matter what is done and what materials are used. They speak of "safer" materials rather than "safe" because every person's sensitivities are so different. When work is to be done at Ecology House, residents are given ten days notice and material safety data sheets (MSDS) for the products to be used are provided. A resident has ten days during which to suggest an alternative material if he or she is concerned about the proposed product's safety. Ecology House is described well on the Web site www.ecologyhouse.org.

HOW DOES ONE CREATE A SAFE LIVING SPACE?

By the time a person comes to you for help she or he may be in an almost impossible situation regarding housing. The person may be homeless, living in a car, or in housing that is making her or him sick. You may hear stories about past and ongoing housing problems. There may be a

need for financial assistance to create even a marginally safe living space. The person needs somehow to create the cleanest living space possible within her or his means.

Assess the Outdoors

The person first needs to assess the outdoor environment of any potential living site to be sure that the area is not subject to fumes from industry, heavy traffic emissions, pesticide spraying by the city or by close neighbors, emissions from neighbors' gas appliances, laundry exhaust and laundry product fumes, or electromagnetic frequencies from cell phone towers or other sources.

Laundry product fumes such as those from scented fabric softeners can be difficult to detect on a single site visit because of their intermittent use. But their presence is important to determine because they can cause severe reactions in some people. Some suggest camping outside for a couple of days at a prospective home to find out if neighbors use such products. However, even if none are detected, people can still change their products and start using them in the future. This is just one example of the tremendous difficulty that people with MCS face in finding housing. Further investigation might involve calls to potential neighbors or to the municipality to inquire about the use of pesticides or other toxics, driving around a large perimeter looking for potential pollution sources, visiting the site at all hours to observe the conditions there, and other methods.

Mold exposures can also be a problem for a person with environmental sensitivities. The presence of molds in residences can be difficult and expensive to deal with. They typically occur in damp areas such as those with heavy rainfall, high humidity, or near oceans or other bodies of water and/or in houses with roof or plumbing leaks or after other flooding.

Cell phone towers, overhead power lines, or similar sources of electromagnetic radiation and electromagnetic fields need to be examined also. For example, it is probably not advisable to lease a second floor apartment with power lines right outside a window and/or a transformer box mounted on the pole in front of or behind the house. Also best avoided is an apartment, condo, or other multi-unit situation where the power panel for the whole complex is on the exterior wall of one of the bedrooms.

Assess the Indoors

The person with MCS needs a home free of ALL petrochemical heat and cooking sources, pesticides, conventional cleaners, solvent-containing paints, formaldehyde-emitting furniture (foam and pressed board), perfumes and air fresheners, tobacco smoke, and other volatile chemicals. Some need the home to be free of animal allergens as well. The house should not be moldy; old homes and those with damp cellars are the most likely to have this problem.

Petrochemical heat is a sensitizer and dangerous for any person with MCS. Even if the heat is indirect (as in radiators where the fuel does not directly enter the living space), you still have the possibility of spills during delivery, leaking tanks, and other accidents that can render a home uninhabitable for someone with MCS. Heat sources need to be electric, solar, or at the very least, hot-water baseboard with the fuel tank outside of the building. Although I still don't endorse this option, some people with MCS live with petrochemical heat if the heat source is at a great enough distance from the living space and the fuel source is not a direct one.

The person should inquire about the pesticide history of a potential home by questioning the landlords, builders, or neighbors. Formaldehyde impregnated building materials such as particle board emit considerable formaldehyde particularly in their first year and continue to outgas for

ten or more years. Better construction materials include exterior grade plywood, as it contains a lesser amount and a less toxic type of formaldehyde (phenol formaldehyde rather than urea formaldehyde). Interior grade plywood may outgas formaldehyde as much as the particleboard. Cupboards and other visible particleboard products can be sealed with less toxic products designed to prevent outgassing of fumes. However, people who have tried this suggest that it might be safer to simply replace particleboard or other composite board cupboards with old-fashioned metal or glass shelves and cupboards or to cover the particleboard with aluminum or steel foil, whatever is tolerated best.

Conventional carpet may emit dangerous volatile organic compounds (VOCs), dyes, formaldehyde, and worst of all, 4-phenyl cyclohexane (4-PC). In October of 1987, the EPA began installing carpet in its Waterside Mall headquarters in Washington, D.C. The EPA received 1,141 health complaints from employees, but unfortunately took two years to remove the toxic carpet. Some employees became permanently sensitized from the experience; some are permanently unable to work in the building, and some are unable to work at all. It appears that the 4-PC may be the most dangerous element in carpeting. People with MCS do best in uncarpeted spaces, i.e., those with tile, brick, wood, or old linoleum floors. For some, older carpet (8 or more years old) may be ok, but for those with dust allergies, no carpet may be tolerable. If a space seems ok except for the carpet, it is sometimes possible to make it tolerable by covering the carpet with cotton sheets or area rugs and or getting permission to remove the carpet while living there.

Choosing a Home and Making it Safe

Once the person has chosen a living spot he or she needs to be as strict as possible about the purity of anything that goes into the home. The more sensitive the person the more careful he or she must be. Making a clean home requires becoming knowledgeable about paints, fabrics, carpet (better not to have any), cleaners, natural bug control, and water and air filters. Although filters do not completely compensate for dirty air or unsafe water, many people with MCS use them to improve their air and water quality. There are a number of types of filters available. While it can be tedious at times, a person with MCS is best advised to learn about them and decide which ones might be useful.

One theme that has emerged in an inquiry by the Chemical Injury Information Network (CIIN) is that some people with MCS attempt to compensate for unsafe homes with filters, supplements, and treatments (Wilson, 2001). People should be discouraged from doing this, as it is rarely possible to make up for an unsafe environment by trying yet another treatment.

HOW TO HELP

- Provide any financial aid possible if needed for cleanup. The person may need air cleaners, water filters, replacement items for unsafe items in the home.
- Guide the person toward resources for non-toxic living. The following resources are an excellent start:

Baker-LaPorte, P., Elliot, E., & Banta, J. (2001). *Prescriptions for a Healthy House: A Practical guide for Architects, builders and Homeowners*. New Society Publishers. www.newsociety.com Phone: 800-567-6772

Berthold-Bond, A. 1999. *Better Basics for the Home: Simple Solutions for Less Toxic Lifestyle*. New York: Three Rivers Press.

Berthold-Bond, A. 1990. *Clean & Green*. Woodstock, NY: Ceres Press.

Bower, L. M. 1995. *The Healthy Household*.

Bower, J. 1997. *The Healthy House: How to Buy One, How to Build One, How to Cure a Sick One*.

Bower, J. 1997. *Healthy House Building: A Design and Construction Guide*.

Bower, J. *Understanding Ventilation: How to Design, Select, and Install Residential Ventilation Systems*.

"Your House, Your Health: A Non-Toxic Building Guide" (VHS video). Note: The Bower books and the VHS video are available from The Healthy House Institute, 430 North Sewell Road, Bloomington, IN 47408. Phone: 812-332-5073; Web site: <http://www.hhinst.com/>

Ingram, C. 1991. *The Drinking Water Book: A Complete Guide to Safe Drinking Water*. Berkeley, CA: Ten Speed Press.

Lawson, L. 1994. *Staying Well in a Toxic World: Understanding Environmental Illness, Multiple Chemical Sensitivities, Chemical Injury, and Sick Building Syndrome*. Lynnword@aol.com Lawson's book is an excellent overview of environmental hazards and has been referred to as "The Silent Spring of the 90s."

Lynn Dadd, D. L. 1990. *Nontoxic, Natural, and Earthwise*. New York: Putnam.

Marinelli, J., and P. Bierman-Lytle. 1995. *Your Natural Home*. New York: Little Brown.

Natural Home, a fairly recently established magazine, is an ongoing source for environmentally friendly living. Debra Lynn Dadd is on the Editorial Advisory Board. Contact them at 201 E. Fourth St., Loveland, CO 80537-5655. Phone: 800-272-2193; Fax: 970-667-8317; e-mail: naturalhome@interweave.com; Web site: <http://www.naturalhomemag.com/>

Olkowski, W., S. Daar, and H. Olkowski. 1991. *Common Sense Pest Control: Least Toxic Solutions for Your Home, Garden, Pets, & Community*. Newtown, CT: Taunton Press.

Pearson, D. 1996. *The Natural House Catalog*. New York: Fireside. This book is a broad overview of environmentally friendly buildings, products, organizations, and resources. Extensive resource list, e.g., there are sixty-seven companies listed just for paint.

Rousseau, D. 1997. *Healthy by Design: Building and Remodeling Solutions for Creating Healthy Homes*. Point Roberts, WA: Hartley & Marks. Described as an "architect in a book" how-to manual for siting, heating, ventilating, water, materials, finishes, etc.

Rea, W. J., and J. Enwright. 1988. *Your Home, Your Health, & Well-Being: You Can Design or Renovate Your House or Apartment to Be Free of Outdoor and Indoor Pollution*. Berkeley, CA: Ten Speed Press.

Rousseau, D., and Wasley, J. 1997. *Healthy by Design: Building and Remodeling Solutions for Creating Healthy Homes*. Point Roberts, WA: Hartley & Marks.

Stein, D. 1994. *Least Toxic Home Pest Control*. Revised Edition. Summertown, TN: Book Publishing Co.

Wilson, C. 1993. *Chemical Exposure and Human Health*. Jefferson, NC: McFarland & Co., P.O. Box 611, Jefferson, NC 28640. Phone: 910-246-4460. Orders: 800-253-2187. An excellent reference to 314 chemicals. Information can be accessed by both symptom and chemical name.

Chapter 5

ACCESS TO PEOPLE AND PLACES

It is almost impossible to have any semblance of a "normal" life if you can't go anywhere. Sadly, people with MCS are often cut off from both people and places. Personal relationships with both family and friends are affected. The inaccessibility of public resources leaves people unable to shop, go to the library, use the park, vote, attend public meetings or religious functions, pursue hobbies, education, or entertainment, or at times even walk down the street.

ACCESS TO PEOPLE

Maintaining relationships with both family and friends poses tremendous challenges given the need to avoid the products of industrial culture that most people depend upon. Constructive relationships with partners, children, extended family members, and friends depend upon the compassion and flexibility of others to make accommodations for the person with MCS. However, many do not understand or deliver the needed changes and/or support that is so sorely needed.

Partnering

Sensitivities can be devastating to some relationships. In my research, most people (80%) in romantic relationships felt that their partners were supportive. But about a third had suffered a romantic break-up since developing MCS, and three quarters of these said that the MCS had contributed to the break-up. Some people had partners who didn't even believe that their sensitivities were real. Building any kind of intimate relationship on such a foundation is almost impossible.

Couples may need to be seen together and offered some education about sensitivities in order to legitimize the condition if there is a disbelieving spouse. Partners need strategies for helping their spouse with MCS cope, for covering tasks that the person with MCS cannot carry out, and support in making difficult adjustments that may involve multiple losses. But most important, they need help to understand that their partner has a disability that is not voluntary, and that demands major efforts and adjustments.

Even if a relationship is a positive one, MCS is a severe stressor on the partner. Activities change, finances are strained, workload for the healthy partner increases, and in some cases family planning is affected. For example, one quarter of the 245 women in my life impact study did not have children. MCS was related to the decision not to have children for half of these women. These women felt that their health was not optimal for carrying a child, that medical offices were inaccessible to them, that they were too poor to afford a child due to their health, and that their child might inherit MCS.

Parenting

Parents with MCS may have a very difficult time doing the traditional activities of parenting such as attending school functions, taking their children to community activities, and allowing other children into their homes. I believe that they can still parent where it counts, but that major adjustments need to be made in navigating their child's relationship to the outer world with the well parent performing many of the community duties. It is very important for all family members to receive education about the sensitivities and to have some guidance regarding strategies for accommodating their family member. For example, adolescent children need guidelines for what they can tell friends who come over ways to ask them to be free of fragrance, fabric softener, mothball fumes, and other irritants.

Extended Family

I asked people with MCS how they felt treated by extended family members. Many reported feeling painfully isolated from families, especially in instances where family members had been asked to be chemical free. Respondents said that their families did not understand the nature of their sensitivities (15%), relatives would not refrain from wearing perfume (12%), and that family members did not believe that the respondent had a true physical illness (7%). A few people were prohibited from discussing their sensitivities in the home, excluded from family get-togethers, seen as malingerers or hypochondriacs, verbally abused, or made fun of. On the other hand some described very loving relationships that did accommodate their disability.

Friendships

Having friendships and community connections without access to buildings and facilities is next to impossible. Community access is so limited for some people with sensitivities that they cannot use stores, parks, libraries, or other public or private establishments. Some people are only able to get food by asking health food store workers to gather items and bring them outside for purchase.

By the time a person comes to you for help, he or she may be seriously despairing due to isolation. Any contact with other people that can be salvaged will be very important. It might take a tremendous effort on your part to get the person to identify something that they can do to increase their contact with others. And the sicker the person is, the less energy she or he has to put into such efforts. If you add that no matter how well the person plans, there is a likelihood of getting sick from exposure on any outing, the difficulty of maintaining community contact is apparent. There is a terrible sadness that comes from a lack of friendships or social support. Abuse from others who do not understand sensitivities may complicate the situation and cause a sense of learned helplessness on the part of the person who feels that relationships are just no longer possible. Serious depression can result from the isolation, and despair from missing the part of self that is relational.

However, I think that it is important for people to know that there are some members of society who do understand that industrial capitalism has harmed people's health, and that some people just need to live differently.

ACCESS TO PLACES

When persons are unable to work, further their education, or enter public buildings, serious quality of life issues are raised. For the MCS population, merely performing errands or participating in environments that others take for granted endangers health. Lack of access to public spaces means that these places are not really public. Although paid for with public funds, they exist for those tolerant enough of toxics and mobile enough in body to make use of them. At this point in time, people with MCS are essentially an invisible population due to the lack of a paradigm for chemically induced illness. The invisibility in public places probably helps to create a vicious cycle in terms of the lack of change or accommodation in regard to these areas.

Perfume is a major toxic that renders public spaces inaccessible for many. In my Life Impact study, almost half of the participants were unable to access any public areas in which perfume was likely to be encountered. The cumulative effects of perfume, exhausts, pesticides, paints, building materials, electromagnetic radiation, and other incitants left 8% of the sample totally housebound at the time of the study.

All of the following public venues and spaces are problematic for many with MCS:

Public parks are not accessible due to pesticide and herbicide use, and others' cooking fuels.

Any public meetings including community meetings and voting are problematic due to fragrance, petrochemical heating systems, cleaners, and pesticides.

Children's school activities are inaccessible to the parent with MCS due to contamination of school air with pesticides, cleaners, construction materials, carpet, petrochemical heating, and fragrance.

Merchants including food stores are not accessible due to fragrance, heating systems, pesticides, and offgassing of contaminants in merchandise such as vinyl.

Offices of health providers have as many toxics as any other public buildings rendering them unusable by those with MCS. Fragrance and pesticide applications are commonplace in physicians' offices, even though pesticides are often hormone disrupters and associated with many forms of cancer including breast cancer and childhood brain cancer.

Street fairs and carnivals are entertainment to many people, but due to fragrance, pesticides, and propane powered cooking and carnival rides, completely inaccessible to people with MCS.

Libraries also may be problematic for people with MCS due to indoor air quality.

Public transportation is affordable transport for some people, but for those with MCS it means exposures to fragrance, petrochemical fumes, and possible pesticides.

Airplanes subject people to fragrance, recycled cabin air, and pesticides (now included in the paint used in the cabin).

Religious activities including church, synagogue, or mosque worship services are problematic because of indoor air quality problems, and most important, fragrance. Many people in my studies have lamented the loss of their religious community due to the community's refusal to limit fragrance at worship.

HOW TO HELP

- Help people identify any potentially supportive others who could be educated about their condition and possibly provide some companionship.
 - Help people brainstorm about any activities they could be involved in with some prior planning, such as outdoor activities, gatherings that are fragrance- free.
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Chapter 6

IDENTITY, SELF, AND PSYCHOLOGY IN MCS

PSYCHOLOGICAL CONSEQUENCES OF MCS

Any mainstream discussion of MCS or electrical sensitivity goes immediately to the topic of whether or not they are psychological. This discussion is ill-informed in that it confuses psychological reactions and symptoms with psychological causation and wastes precious time and energy. It is NORMAL for there to be psychological issues for any person who has experienced a loss. MCS is a long-term drawn out experience of multiple losses for most people. All chronic illnesses and disabilities require adjustments, increase demands, and have psychological consequences. MCS in particular may have a significant psychological overlay accompanying the condition that can cause people to confuse it with a psychological condition. I believe there are a couple of reasons for this. One is that for many the target organ most affected by chemical exposures is the brain. Brain reactions include changes in mood, energy level, aggression level, appetite, ability to think and remember, and many others. Another reason is that MCS is so demanding in terms of the changes it requires and so incongruent with the kind of culture that we live in that people often develop personality changes in response to the stress of having the condition. For those with electrical sensitivities, the problem is even worse. I call these two types of effects the direct and indirect psychological effects of having sensitivities.

Direct Psychological Effects

Direct reactions are those that people experience as a direct effect of chemical exposure, e.g., crying/depression after an exposure to natural gas. Direct effects can include depression, anxiety, panic attacks, irritability, restlessness, confusion, anger, and others. One woman in my research described being outside when pesticides were being sprayed on a neighboring field and becoming so angry that she actually was out of control. From that point on, she experienced this whenever she was exposed to pesticide. Irritability, anger, depression, and panic are common reactions to chemical exposures for those with MCS. It is important for people to be able to identify as many of their direct effects as possible in order to manage their own behaviors. A clear understanding of one's own reactions helps in a) avoiding or escaping dangerous exposures, b) understanding

where a negative feeling is coming from, and c) controlling one's behavior in order to avoid negative consequences. It is very important for people NOT to attribute their chemical reactions to other social or personal variables. For example, if irritability is present from a perfume exposure it is important to understand that this is the cause in order to prevent misbehavior directed at others.

Indirect Psychological Effects

Secondary effects come from having to cope with the direct reactions and with sensitivities in general over a period of time.

Loss. People with MCS often lose relationships, work, hobbies, public access, belongings (because they are intolerable chemically or because of financial loss), their ability to control their physical appearance, travel opportunities, contact with family, and educational or retirement plans. For some it is an ongoing process of losing almost everything. Others are able to make some changes yet preserve the essence of what was important in their lives. But most people with MCS will have some mourning to do regarding loss.

Isolation. Physical isolation is a hardship that compounds the mental isolation of having a misunderstood condition. When added to other stressors such as possible poverty and loss of home and/or work, it can be extremely traumatic. The isolation can be even worse for those with electrical sensitivities because of their difficulty using phones or computers for communication.

Fear. In an industrial society constant vigilance is required in order to avoid chemical exposures. There are no more light-hearted outings when part of the person's attention needs to be on guard for possible devastating exposures. In addition, the person faces uncertainty about the future. Given the "spreading phenomenon" associated with MCS, people know that they may eventually face even more losses with respect to livelihood, home, and physical and even cerebral abilities.

Anger. The loss, misunderstanding, physical symptoms, discrimination, and misdiagnosis naturally lead to anger and frustration. People need ways to process and come to terms with their anger so that it won't control or define them.

Obsessive-compulsive behaviors. For self-protection, people may develop behaviors that appear obsessive-compulsive to those who do not understand the importance of chemical avoidance. Survival with sensitivities may require making phone calls ahead to check on pesticide applications before going to a public place, watching for smokers in a crowd, sniffing for perfume, washing clothing in baking soda to clean out manufacturing chemicals or residual scented laundry fumes, avoiding electrical appliances, and other such protective actions. These behaviors certainly conflict with any type of spontaneity and can cause others to make judgments about people's psychological health that may not be accurate.

Lack of choice about public behavior. If people suffer from brain reactions to chemicals, they may face embarrassment about becoming emotional in public as a result of exposures. Irritability, depression, apathy, and fatigue can all surface from exposures and leave the person with less choice than preferred when it comes to behaviors in public contexts. Neurological reactions are not voluntary.

Lack of privacy about health. For some physical illnesses, privacy exists. However, for visible disabilities and conditions that require workplace accommodations, this privacy does not exist. Co-workers may make negative judgments about people who ask for accommodations perceived

to be unusual. Media programs that debate the legitimacy of MCS or ES cause further anger, frustration, and depression for those who live with it.

Loss of choice regarding a comfortable or chosen lifestyle. People often must make so many changes to cope with MCS that they no longer are living a lifestyle that feels congruent with their sense of self. Yet the changes may all have been necessary for survival. One woman in my research described this problem:

This illness has changed my sense of choice. I think that choice is extremely important. Prior to illness, if I worried over or was unsatisfied with a situation (such as a job), I always felt there were many choices, and I'd be able to change any situation that was difficult or dissatisfying. Presently, I am only able to work out of my home environment, and I am unhappy with my limitations.

Negative attitudes toward authorities/conventional medicine. Those with MCS have generally received such poor treatment from medical providers that they may have anger and distrust toward representatives and practitioners of conventional medicine.

All resources are taken up with coping with health. If all time, money, and energy are consumed by the effort to survive, higher functions such as spiritual and personal growth may be put on hold. Although the person intends for this to be temporary at the time, if the survival crisis is ongoing, those higher needs can remain on hold indefinitely.

The loss of a continued stable sense of identity. Anselm Strauss (1984) has discussed the fluctuations in identity that come as a result of chronic illness. The exposures in MCS often cause brain reactions that feel foreign to the person experiencing them. Since reactions fluctuate there may result a discontinuous feeling of identity. When not reacting, the person actually somewhat forgets the experience of being that sick. But when in the middle of a reaction, previous experiences of wellness and the person's previous base of personal growth and direction cannot be accessed. Identity therefore fluctuates through periods of limbo, when the person waits for reactions to wear off. Relationships are interrupted during these times while others' lives continue. The necessary interpersonal catching up is difficult and the person with MCS may be seen by others as unreliable or as an inconsistent presence.

SELF AND IDENTITY IN MCS

Given all of these challenges, it is difficult to maintain a familiar or viable identity. As with any disability, the person with MCS must come to terms with a new sense of self that includes the disability and honors remaining strengths while letting go of lost abilities. This is very difficult to do in the midst of physical symptoms, financial loss, personal rejection, and loss of roles. Consequently, many have a very difficult time and suffer considerable distress.

Identity Changes

The bad news. My students and I asked people with MCS how their sense of self had been affected by having MCS and categorized the results according to themes. Some expressed feeling dislodged and isolated from everything they had previously depended upon or thought of as self. Others felt resentment at having so little control over not only external life circumstances, but also internal states of mind due to brain reactions to chemicals. This was a source of great suffering for people who had worked on becoming a particular kind of person only to have their

personal growth hijacked by involuntary states of mind such as irritability and confusion. People felt robbed of the lives they had planned; younger people had to leave careers and older people had to scrap retirement plans. People were traumatized by the realization that the MCS could or would eventually rob them of absolutely everything including relationships, career, hobbies, travel, athletics, art, and retirement plans. Not everyone is able to face this realization and find anything positive in it. In fact, most people in their right minds would not find it positive. People struggled with feeling deserted and disconnected to people and to community. Some hit bottom and were not able to recover. Lives disintegrated under the pressure and sadly some wrote of their fear that they would eventually have no option but to commit suicide.

The not so bad news. You can see that the obstacles to be negotiated in the process of coping with MCS are over-whelming. Some people understandably disintegrate under the pressure. But almost surprisingly, some report finding actual personal growth in the experience. People in our research learned new information, developed new skills, found new friends who better understood their problem, found new tolerance for others, grew an appreciation for small blessings that really matter, found self-esteem despite being different, and even grew spiritually from the experience. This group was able to re-build their identity so as to accommodate the MCS and grow either in spite of or because of it. Goodhart and Lansing (1997) in their book on helping people with chronic illness describe these people as the phoenixes rising from the ashes. This is the goal of the advocate who works with people with MCS to increase the probability that they will be phoenixes and somehow thrive in the midst of incomprehensible hardships.

HOW TO HELP

- Help the person identify and take credit for what he or she has done well in regard to coping with MCS. It is an almost impossible task to live a productive life with such a limiting condition. To succeed at all is cause for celebration.
 - Help the person identify brain reactions occurring in order avoid mistakenly attributing them to incorrect sources.
 - Help the person process/face loss, anger, and disappointment. Refer to counseling/therapy if needed.
 - Help the person remember and "keep" the qualities they like about themselves while restructuring the self to include a disability.
 - Help the person learn to value the self by new yardsticks when the old conventional measures of productivity no longer work.
 - Help the person to find creative ways to combat the isolation.
 - Help the person to find creative outlets.
-

Conclusion

You can see that the life impacts of having MCS and/or ES are extensive. Yet people with MCS have found ways of coping even without any cultural support. A number of people with MCS and ES have made tremendous contributions to disability and environmental advocacy and policy. Some of the MCS advocates are people who began support networks when there was absolutely no knowledge or support of any kind for those with these hidden disabilities. How much easier would their paths have been had some support and advocacy been available to them?

Although there are no official data on what percentage of people with sensitivities commit suicide, it happens when the stresses become too severe and the person sees no way out. Many of these people have no money, no home, no support, and certainly no advocates. One supportive person may be a lifeline to someone who is quickly losing her or his place in society.

By informing yourself about MCS and ES you are helping to ease the way for people who could otherwise fall completely through the cracks of our system. You could be the only person in someone's life who actually believes him or her and is willing to listen and brainstorm about possible actions. Having just a basic understanding of the problem and being willing to learn from people with MCS and ES will place you in an excellent position to help.

It is expected that many more people will develop MCS in coming years due to environmental contamination. Many of the people in my study have had MCS for decades (the average time was 15 years). Therefore, if MCS is environmentally caused, many people suffered their initial sensitizing exposure many years ago. How many more people are developing MCS now as a result of increasing air, water and food contamination? And events such as the World Trade Center destruction set up large portions of the population to develop environmentally induced illnesses that may or may not develop into MCS. It is crucial that our institutions recognize and respond to the plight of these people in order to be positioned to help the increasing numbers who will request help. However, I do not expect that this recognition will begin in the hierarchical/professional institutions such as universities and medical centers, but rather in grassroots types of settings where people have ongoing contact with people with the problem. The MCS support groups have begun the fight for recognition of this disability. centers for independent living are perhaps the next level where this work can continue with your help.

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