UNDERSTANDING & ACCOMMODATING MULTIPLE CHEMICAL SENSITIVITY

A National Teleconference

Participant’s Manual

February 20, 2002

Contributors to the training materials:

Pamela Gibson, Ph.D.  Mary Lamielle
Melanie Lyle          Melissa Kaplan
Darrell Lynn Jones    Raweewan Buppapong
Kristy Langbehn       Carri George
Richard Petty         Dawn Heinsohn
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About the Trainers

Pamela Gibson, Ph.D. is Associate Professor of Psychology at James Madison University and has been researching the life impacts of multiple chemical sensitivity since 1992. Her MCS research has resulted in several journal articles, a number of conference presentations, and the self-help book *Multiple Chemical Sensitivity: A Survival Guide* (New Harbinger Publications, 2000). Dr. Gibson earned her Ph.D. in clinical psychology in 1991 from the university of Rhode Island.

Mary Lamielle is Executive Director of the National Center for Environmental Health Strategies, Inc., based in Voorhees, New Jersey, where she provides clearinghouse services, technical assistance, policy development, research, and advocacy for those injured by chemical and environmental exposures. She is frequently sought after as an MCS expert by television/radio, newspapers, professional journals, as well as Congress.
Trainers

**Pam Gibson, Ph.D.**  
Associate Professor of Psychology  
James Madison University  
MSC 7401  
Harrisonburg, Virginia 22807  
540-568-6211, ext. 6195 (Voice)  
540-568-3322 (FAX)  
E-mail: gibsonpr@jmu.edu

**Mary Lamieelle**  
Executive Director  
National Center for Environmental Health Strategies, Inc.  
1100 Rural Avenue  
Voorhees, New Jersey 08043  
856-429-5358 (Voice)  
E-mail: ncehs@ncehs.org
IL NET STAFF

ILRU
Lex Frieden
Executive Director
lfrieden@ilru.org

Laurie Gerken Redd
Administrative Coordinator
lredden@ilru.org

Richard Petty
Program Director
repetty@compuserve.com

Carri George
Publications Coordinator
cgeorge@ilru.org

Laurel Richards
Training Director
lrichards@ilru.org

Dawn Heinsohn
Materials Production Specialist
heinsohn@ilru.org

ILRU Program
2323 S. Shepherd
Suite 1000
Houston, TX 77019
713-520-0232 (V)
713-520-5136 (TTY)
713-520-5785 (FAX)
ilru@ilru.org
http://www.ilru.org

NCIL
Anne-Marie Hughey
Executive Director
hughey@ncil.org

Kristy Langbehn
Project Logistics Coordinator
kristy@ncil.org

NCIL
1916 Wilson Boulevard
Suite 209
Arlington, VA 22201
703-525-3406 (V)
703-525-4153 (TTY)
703-525-3409 (FAX)
1-877-525-3400 (V/TTY -
toll free)
nncil@ncil.org
http://www.ncil.org

Darrell Lynn Jones
Training Specialist
darrell@ncil.org

Raweeewan Buppapong
Project Assistant
toony@ncil.org
ABOUT ILRU

The Independent Living Research Utilization (ILRU) Program was established in 1977 to serve as a national center for information, training, research, and technical assistance for independent living. In the mid-1980’s, it began conducting management training programs for executive directors and middle managers of independent living centers in the U.S.

ILRU has developed an extensive set of resource materials on various aspects of independent living, including a comprehensive directory of programs providing independent living services in the U.S. and Canada.

ILRU is a program of TIRR, a nationally recognized, free-standing rehabilitation facility for persons with physical disabilities. TIRR is part of TIRR Systems, a not-for-profit corporation dedicated to providing a continuum of services to individuals with disabilities. Since 1959, TIRR has provided patient care, education, and research to promote the integration of people with physical and cognitive disabilities into all aspects of community living.

ABOUT NCIL

Founded in 1982, the National Council on Independent Living is a membership organization representing independent living centers and individuals with disabilities. NCIL has been instrumental in efforts to standardize requirements for consumer control in management and delivery of services provided through federally-funded independent living centers.

Until 1992, NCIL’s efforts to foster consumer control and direction in independent living services through changes in federal legislation and regulations were coordinated through an extensive network and involvement of volunteers from independent living centers and other organizations around the country. Since 1992, NCIL has had a national office in Arlington, Virginia, just minutes by subway or car from the major centers of government in Washington, D.C. While NCIL continues to rely on the commitment and dedication of volunteers from around the country, the establishment of a national office with staff and other resources has strengthened its capacity to serve as the voice for independent living in matters of critical importance in eliminating discrimination and unequal treatment based on disability.

Today, NCIL is a strong voice for independent living in our nation’s capital. With your participation, NCIL can deliver the message of independent living to even more people who are charged with the important responsibility of making laws and creating programs designed to assure equal rights for all.
ABOUT THE IL NET

This training program is sponsored by the IL NET, a collaborative project of the Independent Living Research Utilization (ILRU) of Houston and the National Council on Independent Living (NCIL).

The IL NET is a national training and technical assistance project working to strengthen the independent living movement by supporting Centers for Independent Living (CILs) and Statewide Independent Living Councils (SILCs).

IL NET activities include workshops, national teleconferences, technical assistance, on-line information, training materials, fact sheets, and other resource materials on operating, managing, and evaluating centers and SILCs.

The mission of the IL NET is to assist in building strong and effective CILs and SILCs which are led and staffed by people who practice the independent living philosophy.

The IL NET operates with these objectives:

- Assist CILs and SILCs in managing effective organizations by providing a continuum of information, training, and technical assistance.

- Assist CILs and SILCs to become strong community advocates/change agents by providing a continuum of information, training, and technical assistance.

- Assist CILs and SILCs to develop strong, consumer-responsive services by providing a continuum of information, training, and technical assistance.
Multiple Chemical Sensitivity and the Workplace

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WHAT IS MCS?
People with multiple chemical sensitivity (MCS), also known as multiple chemical intolerance (MCI), report extreme sensitivities or intolerances to a wide range of exposures from new carpeting and particleboard to pesticides and cleaning agents. Reactions are triggered by common, low-level chemical exposures. Many people report symptoms from contact with foods, medications and natural substances. Some people also report electrical sensitivity (ES) to electrical devices and frequencies. This complex condition may also be referred to as “environmental illness” (EI).

What Are the Symptoms of MCS?
People with MCS report symptoms involving one or more organ systems characterized in part by neurological impairment, respiratory involvement, muscular pain and weakness, cardiovascular problems and/or gastrointestinal complaints. Symptoms reported by those with MCS may include:

- Severe headaches
- Fatigue
- Short term memory problems
- Difficulty concentrating
- Confusion and disorientation, sometimes referred to as “brain fog”
- Problems with spelling, math, writing or processing information
- Flu-like symptoms with headache, dizziness, nausea and muscle aches and pains
- Balance problems and vertigo
- Difficulty breathing, hoarseness, upper airway infections, reactive airway disease, bronchitis and asthma
- Cardiovascular problems with irregular or rapid heartbeat, chest discomfort and flushing
- Muscle and joint pain and weakness; muscle twitching
- Numbness, particularly in the extremities
- Gastrointestinal problems
- Visual disturbances
- Seizure disorders including collapse and paralysis
- Variety of skin conditions including rashes
- Heightened sense of smell
- Mood changes ranging from irritability and anxiety to depressed feelings

MCS: A Two-Staged Illness
Those with chemical sensitivities experience a spectrum of problems from mild, irritant level reactions to the severe, disabling symptoms of MCS.

Those with MCS have a chronic condition with symptoms triggered by chemical and environmental exposures on a day-to-day basis.

Many people with MCS report a new onset of symptoms following an initiating exposure event. Some people report prolonged, repetitive or cumulative, low-level exposures such as poor air quality with inadequate ventilation as the cause of chronic illness. Others are unable to point to one exposure or are unaware of a specific exposure event that may have sparked their illness.
Once chronically ill, reactions are not only triggered by contact with the initiating exposure, but by contact with more and more different substances and products at lower and lower exposure levels. Many people report food intolerances as well as reactions to food colorings, additives, preservatives and pesticide residue. They may also report increased problems with classic allergens such as molds, over-the-counter and prescription medications, and various natural substances.

What Causes MCS?
The following exposures have been identified as initiating or causing MCS:

- Pesticides: chemicals used to kill insects, weeds and termites, for example
- Chemicals used to disinfect or to kill molds
- Cleaning agents such as floor waxes and carpet shampoo
- Poor air quality due to new construction, renovation, remodeling or inadequate ventilation
- Fresh paint
- New carpet and adhesives
- Formaldehyde in cabinets and particle board
- Mattresses
- Carbonless paper
- Emissions from office equipment such as copy and fax machines, ink or laser printers
- Asphalt and roofing processes
- Chlorine and chlorinated products; toluene, xylene, and other solvents
- Freon
- Gluteraldehyde used in hospitals and health care facilities
- Plastics
- Sewer gases
- Cutting Oils
- Fuel oil and other chemical spills
- Combustion sources and combustion by-products including tobacco, natural gas, oil heat, propane, woodstoves, kerosene heaters, etc.
- Perfumes, scents and scented products
- Anesthesia, antibiotics and other medications
- Molds

What Are the Common Exposures that Trigger MCS Symptoms?
People who develop MCS experience symptoms triggered by the initiating exposure or exposures as well as by an increasing number of everyday substances and products. These may include:

- Adhesives and glues
- Air fresheners and deodorizers
- Ammonia
- Asphalt
- Auto and diesel exhaust
- Auto interiors
- Bug sprays, weed killers and other pesticides
- Carbonless or treated paper
- Cleaning agents, particularly chlorine or phenol-based, and/or scented products
- Detergents, fabric softeners and dryer sheets
- Disinfectants
- Dry cleaning chemicals
- Felt tip pens and markers
- Hair care and personal grooming products
- Hand lotions and sanitizers
- Latex
- Leather
- Manufactured or veneered wood
- Mattresses and upholstered furniture
- Mothballs
- Nail polish and remover
- Natural gas and propane stoves
- Newsprint and inks
People with MCS experience symptoms in the workplace, in schools, grocery stores, hair salons, department stores, malls, building supply and lawn care centers, health care facilities, hospitals, churches, hotels/motels and in most homes. New or recently remodeled buildings and facilities generally pose significant chemical barriers. Symptoms may occur following inhalation, ingestion or skin contact. They may be triggered by exposure levels well below OSHA standards, below odor threshold levels.

Who is Affected by MCS?
MCS has been identified in different demographic groups in the U.S. and in over a dozen other countries. People with MCS come from all walks of life. Populations reporting heightened reactivity to chemicals include:

- industrial workers;
- occupants of buildings with poor air quality or inadequate ventilation including office workers and schoolchildren;
- people in contaminated communities whose air or water is highly polluted;
- people who have had a personal and unique exposure in the home environment to pesticides, pharmaceuticals and consumer products;

What Are the Characteristics of MCS?

- Symptoms come and go depending on exposure.
• people in the vicinity of a massive chemical spill; and
• people exposed to chemicals and other substances during military conflict or terrorist attacks.

**What is the Prevalence of MCS?**

Surveys conducted by the California Department of Health Services, the New Mexico Department of Health, medical researchers in North Carolina and the U.S. EPA found that between 15 and 30 percent of the people surveyed reported being “unusually” sensitive or “especially” sensitive to certain chemicals. Those who reported significant daily impairment from chemical exposures in population-based surveys ranged from 2 percent in New Mexico to 4 percent in California and in North Carolina. 11.9 percent of those surveyed in California described sensitivities to more than one type of chemical; 6.3 percent reported doctor-diagnosed MCS/EI.

A separate California Department of Health Services survey found that 3 percent of respondents reported that they were unusually sensitive to electrical appliances and power lines.

Most experts agree that the prevalence of MCS is on the rise.

**Diagnosing MCS**

Although numerous definitions for MCS have been used within a scientific framework for research purposes, there is no one diagnostic test that identifies the MCS patient. The underlying mechanism remains a mystery.

Most people experience a significant decline in the level of health and well being subsequent to an initiating exposure event. MCS patients seeking medical assistance may first contact their primary care physician.

In the absence of educational materials designed to inform the medical community, primary care physicians may have difficulty understanding or responding to the patient’s needs. Physicians may treat specific symptoms without understanding that these problems are triggered by a host of everyday chemical and environmental exposures. Some patients report bringing materials to the physician in an effort to educate the medical professional and enhance the doctor-patient relationship.

It is critical that the physician take a careful and comprehensive medical history including information on occupational and workplace exposures, hobbies and home life. The physician should ask about and document reactions or intolerances to chemicals, foods, especially caffeine and alcohol, medications, molds and natural substances before and following a suspected initiating exposure. The patient should keep a diary in response to the questions: What am I breathing? What am I eating? What am I touching? and How am I feeling?

Physicians who have experience evaluating and treating those with MCS include some occupational and environmental health specialists, frequently members of the Association of Occupational and Environmental Clinics (AOEC) located in Washington, DC, and members of the American Academy of Environmental Medicine (AAEM), Wichita, Kansas. Members of the AAEM, also referred to as environmental medicine physicians, have historically recognized and evaluated patients with MCS.

It is critical that patients carefully evaluate what the medical community offers in this area to be certain that they see health care professionals who are most appropriate to their circumstances.

**Treatment Options**

There is no cure for MCS although a number of treatment options may help improve the overall health of those with this condition.
Avoidance is the cornerstone of any effective treatment plan. MCS patients should:

- avoid exposures that trigger reactions;
- consider low or no cost modifications to the home and workplace to minimize exposures; and
- take advantage of professional and peer counseling as well as support services as available. These services may help ease the isolation from family and friends and the loss of self-esteem experienced by many with MCS and ES due to their inability to participate fully in society as the result of chemical and electrical barriers.

The absence of medical and government support may cause additional anxiety and intensify the symptomology. Medications may offer little or no relief and may actually intensify or trigger additional symptoms. Few people sick from MCS report full recovery even decades after becoming sick.

Recognition of MCS

The first Congressional testimony on chemical sensitivities was presented at hearings on the Indoor Air Quality Act in 1989. In 1992 Congress appropriated $250,000.00 from the Superfund budget for chemical sensitivity research. The United States Department of Housing and Urban Development contributed $800,000.00 toward construction of “Ecology House,” an 11-unit apartment building in San Rafael, California, tailored to the access needs of those with MCS and related conditions. The complex opened in November 1994.

MCS is increasingly recognized as a disability. Internal memoranda at the Social Security Administration, Program Operations Manual, February 1988, and the Department of Housing and Urban Development, April 1992, recognize MCS for the purposes of compensation and housing accommodation respectively.

The Americans with Disabilities Act (ADA) states that some of those with MCS may have neurological, respiratory, or other functions so severely impacted that it substantially limits one or more major life activities. These individuals are protected by the ADA.

Revisions to the ADA Accessibility Guidelines for Buildings and Facilities to be issued by the U.S. Architectural and Transportation Barriers Compliance Board, also referred to as the “Access Board,” in 2002, will include preamble language that addresses the needs of those with multiple chemical sensitivities and electrical sensitivities. Final Accessibility Guidelines for Recreational Facilities will include similar language.

The Board adopted a Fragrance-Free Policy for its meetings in July 2000. The Access Board also plans to develop technical assistance materials on best practices for accommodating individuals with this disability.

In a separate initiative the Access Board intends to fund a project on indoor environmental quality to examine building and construction practices that impact on the indoor environment and to develop a plan of action that can be taken to reduce the level of chemical and electrical exposures in the built environment.

The most recent statistics from the Equal Employment Opportunity Commission (EEOC) indicate that from November 1, 1993 through June 30, 2001, 634 MCS discrimination charges were filed. The agency found cause in 26 charges but has not yet litigated an MCS complaint. MCS complaints for failure to accommodate employees (59%) are nearly double non-MCS charges (31%). MCS complaints also have a lower resolution rate than other discrimination complaints.

The terms multiple chemical sensitivity and environmental illness now appear on the
National Library of Medicine’s bibliographical database MEDLINE.

**A Preventable Disability: The Importance of Early Intervention**

MCS may be a preventable disability. Early intervention is critical. Accommodations to address the needs of employees with chemical and electrical sensitivities are essential to avoid permanent disability.

Many accommodations are modest and inexpensive and can be accomplished with common sense. The affected individual is frequently the best judge of what needs to be done to facilitate accommodations. To begin this process, the employee should:

- identify exposures that must be addressed;
- request product labels and Material Safety Data Sheets (MSDS) for troublesome building materials and supplies; pesticides and cleaning products, as available;
- determine specific accommodations or alterations that may be necessary;
- seek advice from MCS educators/advocates, knowledgeable indoor air experts, union leaders, supportive coworkers and others;
- discuss proposed accommodations with physician and request a letter of support; and
- arrange to meet with supervisor or employer to discuss accommodation requests.

Employers should understand that there is no single action that will accommodate all of those with MCS. They will need to listen to the employee’s requests and work with the individual to achieve a successful outcome.

**Accommodating those with MCS**

Cost effective intervention measures can help the employee with MCS avoid problematic and debilitating exposures while creating a healthier workplace for everyone.

The following is a sampling of successful workplace accommodations.

- provide a private office with a window that opens;
- retrofit windows to make them operable;
- increase fresh air supply and circulation;
- remove carpeting;
- move office equipment such as fax machines, copiers and laser printers from the immediate work environment;
- use odorless, nontoxic cleaning agents;
- provide employee with the cleaning schedule;
- give the affected employee the option to clean her/his own office space;
- select the least toxic/allergenic/unscented construction and maintenance materials, furnishings and supplies;
- off gas all new materials, furnishings and supplies before installation;
- ask affected employees to check the suitability of these items before use in the work environment;
- use metal desk and shelving in lieu of veneered wood or particle board;
- do not use air fresheners, deodorizers and disinfectants which introduce contaminants into the workplace;
- eliminate the use of synthetic pesticides indoors and outdoors;
- if pesticides are used, post permanent notices at building entrances noting the last date of pesticide application, name of applicator, as well as the product and chemical name; post warning notices outside when pesticides are applied;
- provide prenotification of building events such as remodeling and renovation activities, roofing, use of floor wax or pesticide applications;
• educate management and coworkers as to the nature of the disability to avert stigma and harassment;
• provide schedule options so that affected employee can work when fewer coworkers are present, when the ventilation is working at its peak, or where the surroundings are least problematic; and
• the option to work at home.

Requests for equipment and assistive technology may include:
• masks, respirators or other personal protection equipment;
• oxygen;
• charcoal, HEPA (high-efficiency particulate air), and electronic air filters or other air filtration devices;
• reading box;
• low emission computers, VDT terminals and other equipment;
• localized exhaust for computers, printers and other equipment;
• incandescent lighting in lieu of fluorescent or halogen lighting;
• individual control of lighting, ventilation and thermostat;
• special provisions for attending training or meetings by speaker phone or other means;
• an assistant or errand runner who can take care of tasks that the affected employee cannot perform due to exposures.

Funds to provide personal equipment and assistive technology for employees with MCS may be available through a number of government programs.

Cleaner Air Signage
On November 28, 2001, the California Building Standards Commission adopted Cleaner Air Signage to be used voluntarily to identify a room, facility and paths of travel that are accessible to and useable by people who are adversely impacted by airborne chemicals or particulate(s) and/or the use of electrical fixtures or devices. The pictogram, a six-point pinwheel design, will be used for publicly funded facilities or any facility leased or rented by the State of California. Use of the signage will signify that minimum conditions for use are met. Compliance will signify control of many environmental triggers that impact on those with chemical and electrical intolerances. Signage will be removed if the minimum conditions for use are not met. A log will be maintained on site to record any cleaning, maintenance, pest control practices or construction activities that may compromise the air quality.

In December 2001 ANSI, the American National Standards Institute, A117 Committee on Architectural Features and Site Design of Public Buildings and Residential Structures for Persons with Disabilities, part of the International Code Council, approved the Cleaner Air Symbol to identify spaces providing lowered levels of airborne contaminants.

Fragrance-Free Policies
Increasingly, employers as well as school systems, colleges, government entities, organizations, communities and others are adopting fragrance-free policies. Some of these policies have been adopted as part of the business or school dress code. For others, a fragrance-free work environment is part of a health and safety or indoor air quality program. Signs may be posted asking that building occupants: Refrain from Fragrances and Fragranced Products or Refrain from Scents and Scented Products. Hair spray and some hair care products, hand lotions, shaving creams, after shaves, fabric softeners, dryer sheets, and deodorants may contain fragrances. Employers and others should also eliminate the use of fragranced soaps, sprays and dispensers in restrooms as well as in the building or the ventilation system.
Successful Accommodations
An Educational Kit distributed by the President’s Committee on Employment of People with Disabilities describes accommodations provided by the employer of an insurance claims adjuster with chemical sensitivities.
- The ventilation system in the employee’s private office was modified;
- Coworkers were asked not to use scented products.
- The employee was permitted to attend staff and training meetings remotely by speaker phone; and
- The employee was given permission to wear a mask when needed.

The total cost was $650.

In a separate accommodation, fluorescent lights were changed to broad-spectrum lights by using a spectrum kit. The cost was $1,065.

In a study done by Cornell University, 32% of private employers reported providing access to people with disabilities by “removing volatile/scented substances” while 48% of employers in the public sector took similar action.

Employers are encouraged to work with the affected employee in an effort to determine a suitable workplace environment. This may take time. Each situation may be somewhat different. Keep an open mind and trust the employee to assist in identifying modifications or alternatives that are most likely to resolve the problem.

Some Employers Fail to Understand MCS
Employers and supervisors, as well as coworkers, may lack an understanding of MCS and its implications. In other instances management and employers may regard the MCS employee’s request for assistance and accommodation as a “power play.” The MCS employee may also be viewed as a malingerer trying to take advantage of the system.

During a disability training session many attendees reacted to the topic of MCS with blank stares. Several audience members stated that they regarded those with MCS as malingerers. They admitted that they would use more perfume if a coworker with MCS asked that they minimize or refrain from wearing scents.

Employers must help coworkers understand that requests made by or on behalf of those with MCS are made to address serious health problems. They are not individual preferences. Failure to respect these requests or to disregard them can have devastating consequences.

MCS Employees Face Harassment and Discrimination
If the employer or management fails to understand or support the needs of the employee with MCS, this may create or sanction an atmosphere of harassment and retaliation. The affected employee may face overt ridicule and derision including intentional chemical or electrical exposures, name-calling, threats and hate e-mail as well as more subtle taunts and challenges. The employee may be ostracized by coworkers and management.

Harassment can take many forms. The following is a sampling of incidents reported by employees with multiple chemical sensitivities and electrical sensitivities.
- Intensified use of perfume or the use of perfume or other scented products during the workday;
- Perfume poured on chairs;
- Deodorizer sprayed on the affected employee’s phone;
- Use of candles in the workplace;
- Use of cell phones and microwave ovens in the vicinity of an electrically sensitive employee;
- Signs that request an accommodation, such as a request to refrain from perfumes, that name the affected employee;
- Employees forbidden to open windows;
- Windows nailed shut to prevent opening;
- Affected person forbidden to use oxygen or mask;
- Active denigration of the affected employee’s abilities in private and in front of coworkers;
- Employees purportedly “accommodated” by selecting the worst possible worksite: an employee sick from various exposures in the workplace is moved into the janitorial closet; a teacher with MCS is moved near the copy center or assigned to the art classroom.

Given such circumstances, some employees with MCS/ES are reluctant to disclose their condition and suffer in silence.

**MCS and the ADA**

The Americans with Disabilities Act (ADA) requires that an employee disclose her/his disability in order to qualify for an accommodation. The employee has a legal duty to cooperate and participate in a good faith accommodation process. While accommodations are explored, the employee still has the obligation to perform the essential functions of the job. The employee may not reject a reasonable alternative nor insist on a single accommodation when other less desirable solutions are available.

This course of action may not work best in an MCS accommodation. The preferred accommodation may be necessary to allow the individual to perform the job with less discomfort and distress from problematic and debilitating exposures. Many times such accommodation requests are practical and inexpensive and cause no hardship for the employer.

Fulfilling such requests enhances the workplace environment for those with MCS and coworkers.

Employers must understand that there is often a narrow opportunity to accommodate the affected employee: the time between when the employee initially experiences intolerances to workplace exposures and when the individual is no longer able to function in the environment, even with significant modifications.

By the time an employee is disabled with MCS, the employee may not be able to work in any environment. The employee’s health may be so compromised that she/he is unable to perform the essential functions of the job. At that time nearly all workplaces will cause insurmountable problems.

Employers need to take a comprehensive approach toward the removal of environmental barriers through education, accommodation and compassion. Actions to improve environmental access are in the best interest of all employees.
Multiple Chemical Sensitivity
A Survival Guide
Chapters 3 and 13

By Pamela Reed Gibson, Ph.D.

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Multiple Chemical Sensitivity: A Survival Guide
Chapter Three
By Pamela Reed Gibson, Ph.D.

How Lives Are Affected by MCS

With all the medical controversy about whether MCS is "real" or not, the people who suffer have been left to fend for themselves. People with MCS are falling through the cracks and becoming an "invisible" disabled minority whose lives are no longer compatible with any of our medical, educational, or social institutions. For some, the suffering is immense. Others, who are more mildly affected, are able to make minor or moderate changes that allow them to live more or less "normal" lives (Gibson, Cheavers, and Warren 1996).

The story of those who are falling through the cracks must be told for several reasons. First, it is important to label the suffering and thus raise awareness about this hidden minority in the hope of drawing support for those who are suffering. It also is important for higher functioning people with MCS to understand the importance of preserving their current level of functioning. Knowing that you may become totally disabled without chemical avoidance and proper self-care can cut through denial and may help you to take your condition seriously.

Also, a commentary on our society has to be made when it permits a substantial portion of its people to become disabled from toxicants to preserve the economic status quo. This chapter discusses the many impacts on everyday life that result from having MCS, including the areas of work, finances, housing, family planning, public access, and quality of life issues.

Although it can be depressing to think about these issues, this introduction might be an excellent summary to share with therapists and with friends and family members who are trying to understand what you are up against. If you are already too familiar with the difficulties of MCS patients, you might want to skip to chapter four and begin working on cleaning up your home.

Another point should be made about the impact MSC has on daily life: The research and reports on the difficulties of living with MCS are very real and, for some, are devastating. However, the summary statistics are just that—summaries of information from many people. The statistics do not predict anything about any particular person. There are many people with MCS who function well in spite of the condition. They maintain relationships with friends and lovers, have satisfactory jobs, live in safe houses, and feel satisfied with their lives. As you will see in chapter fourteen, some even believe that having MCS has contributed substantially to their personal and
spiritual growth. Therefore, keep in mind when you read the information in this chapter that it does not necessarily predict anything about your present or future experience.

**What Happens When You Are Chemically Injured?**

There is no aspect of life that is totally immune to the impact of MCS. People with MCS report that it affects their work, finances, housing, physical access, social relationships, and future plans. The remainder of this chapter reviews these changes. (See chapter eleven for more on social relationships.)

**On the Job**

Depending on your level of chemical sensitivity, work is likely to be very affected when you develop MCS. People with mild or moderate sensitivities often can make minor adjustments and continue to work. As a rule, however, there is some stress involved in obtaining the needed accommodations in the workplace. Often, people who are very sensitive are unable (at least temporarily) to continue in their present jobs. This is especially true if the person was first injured in the workplace. In my research, more than half of those who reported an initial known exposure, which damaged their health, said that it occurred in the workplace. Fewer than one-third of Phase I participants were still working outside of the home. Unfortunately, three-quarters of those who had been working had to quit their jobs to avoid further chemical exposures.

For example, one woman who worked as an advertising consultant often had to conduct her business in office buildings, graphic arts departments, and printing plants. With the onset of MCS, she became reactive to “almost everything” she “ate, breathed, or touched.” Having to avoid the chemicals in print shops and offices meant losing all of her clients. Her computer and electronic devices had to be removed from her home as well; the only electronic appliance she was able to tolerate was a very small, old black-and-white TV. All her attempts to keep working failed.

In another instance, a man went from working as a chemist with a large salary to being disabled, unable to work, homeless, powerless, and ostracized by his family. Fortunately, he did find a safe apartment eventually. Only about one-fifth of Phase I participants who worked were working under conditions they considered safe for their health.

Trying to avoid chemicals in the workplace can lead to increased stress in relationships with co-workers because they may not be cooperative when asked to discontinue using fragrances or other personal care products that are sources of difficulty for those with MCS. Eventually the consequences for the MCS worker are major, as they were for this woman:

> “Working near smokers, perfume users, in moldy, dusty areas, and the refusal of everyone involved to understand or moderate behavior has determined my life course. [This has been] very unsatisfactory to me and has left me destitute...”
financially. Limping along, struggling from exposure to exposure, from job to job, has created an insurmountable obstacle to my accomplishing what I wished I could carry out.” —Sixty-two-year-old woman with MCS since childhood

Many respondents were devastated by the thought of giving up work in a culture that so emphasizes “productivity.” One woman with MCS said:

“I have found it very difficult to hold up without the outside reinforcement that the working environment provided me. Without the reinforcement that I got at work, I began to feel resentful and even worthless.”

Consequently, some people pushed themselves far beyond what their bodies could endure, unable to accept the loss of employment. One woman with MCS said:

“I was interviewing for new jobs and wondering at each interview how I was going to work in this particular building when my body was going into spasms. I was having trouble breathing, and I was having trouble tolerating the place for the hour or two of the interview. In today’s lingo, I still hadn’t ‘gotten it.’”

It seems that chemical injury can occur in almost any job context, although homemakers, clerical workers, students, teachers, nurses, and social workers were most heavily represented in my study. (See Appendix A for the occupations of Phase III participants at the time of chemical injury.)

The accommodations that they were able to obtain at work differed. Obtaining the necessary accommodations mostly depended upon the sensitivity of the employer. Some people received no help and were even ridiculed for asking. Others were allowed to work in safer parts of buildings, at off-hours, or partly at home. Some were even able to create ways to earn money at home. For example, one woman did child care for children whose clothes were washed in safe soaps without fabric softener. Some started small businesses relating to MCS, such as consulting; or they made or sold useful products like masks, supplements, purifiers, or other chemically safe items.

**Finances**

Multiple chemical sensitivity has been described as a “rich person’s disease” because of the tremendous financial demands it places on people. The need to avoid chemicals often means replacing clothing, furniture, bedding, even homes, as well as purchasing purifiers and nutritional supplements. Conventional medical care for MCS at this point is seldom described as helpful and often as downright harmful (see chapter six), and alternatives are often not covered by insurance (see chapter seven). So, for the sufferer, just as income may be declining, costs are escalating.

Income declines drastically for anyone who can no longer engage in full-time work. Although household annual income for my research sample averaged about $35,000,
average personal income for participants was just a little more than poverty level (about $12,000). People suffered sharp declines in their income after losing jobs, and much of their income after leaving work was from disability payments. People with partners who had good incomes suffered the least as they were able to stop work without completely devastating their finances. Others pushed themselves to keep working in spite of their illness because their families depended on them. One man described dragging himself to work to support his family, and spending virtually all of his off time recovering from exposures. Some people were caught in a downward financial spiral and were afraid of becoming homeless. One woman lamented, “It has been very hard on my children. They cannot understand why we don’t have what we used to when I worked or why we’ve lost our car, cable TV, and next will be the telephone. It’s worse for the thirteen-year-old.”

Those who became sensitized later in life seemed to suffer less financial devastation because they had time to build up some savings. One woman explained:

“I came down with MCS later in life so we were able to live a great lifestyle most of our married life. For this I am grateful—I feel I missed very little and am not terribly discontented staying home. We have a lovely home, and more than adequate friends—good friends. Although once in a while I feel sad to have [MCS]. Our HEAL support group has been a lifesaver.”

People who are chemically injured while young never have a chance to build up a financial cushion, and thus are hit very hard. It is important for those with MCS to consider this information when planning for their future. For example, the $10,000 you may spend on a new therapy must be considered in the context of your overall financial health. Consider whether you have a large enough nest egg to experiment so that you won’t be financially devastated if the therapy doesn’t work.

**Housing**

People try to avoid chemical exposures by replacing household items, such as carpets, formaldehyde board, plastics, and other items. But many are unable to afford these replacements. Consequently, some people reported either continuing to live in unsafe conditions, or spending their life savings redoing their homes and purchasing air purifiers or other necessities. Some spent almost $28,000 to clean up their homes, and only two-fifths were living in homes rated as safe. Some respondents reported being unable to tolerate any traditional housing due to chemicals used in construction, and they lived in very unusual conditions.

For example, one respondent had lived in her horse trailer for a year. Others described being homeless or living in their cars, in RVs, in one purified room in their house, or in tents. Many did stints on their friends’ porches or in the homes of their parents. In Phase II, two-thirds of the participants had lived in highly unusual conditions at some point to
avoid chemical exposures. It seems MCS brings out the survival instinct and forces one to be unusually resourceful.

“I live in a tent all summer (May to November). I can tolerate [temperatures] to twenty degrees, so [I] stay as long as possible. In winter, I have [a] room that only has a bed, wood floors, and no heat for my safe room.”

—Forty-seven-year-old man with MCS for five years

Many people wrote to me asking if I knew of safe housing. I know of none. People with MCS are trying to find niches for themselves with very little help from our society. Many have already fallen through the cracks, and others fear that they will too. Probably no one has brought this home to us more so than Rhonda Zwillinger (1997) in her photo-essay of homeless people with MCS entitled, The Dispossessed: Living with Multiple Chemical Sensitivities.

Although there are some projects on the table for creating safe housing, this is extremely difficult because people vary so much in regard to their sensitivities. Constructing housing that is safe for all people with MCS is almost impossible. Some people move to the country to avoid city industries only to face agricultural chemicals. Others move to suburbs and then must confront their neighbors’ lawn chemicals. Renting an apartment is difficult because you cannot control chemical use by your neighbors or the proprietor, and thus may be exposed to smoke, propane cooking, herbicides or pesticides, and fabric softeners. Some people were fortunate to be able to construct safe houses with some buffer against others’ pollution, but it takes considerable resources to do this. Some moved almost continually in search of a clean area only to find that pollution is virtually everywhere.

On the other hand, moving into a safer setting helped a lot of people considerably. One woman had suffered a series of environmental insults including beauty school, and formaldehyde exposures in multiple settings. She had endured two ineffective sinus surgeries prescribed for chemically induced nose, head, and shoulder pain. She wrote, in Phase II of my research: “I try to be positive but there were only sixty days from January through November that I was without pain in 1993.” A move to a cleaner area and discontinuing a job with formaldehyde exposure set her on a healthier course. By Phase III of the follow-up study, she was traveling in a converted van to visit family (13,000 miles in one year) and said, “I am very lucky to be as well as I am. I don’t have ‘the old pain’ anymore. But I do have to be on guard for smells every day.”

I believe that housing is the single most important issue regarding MCS. A safe zone can help prevent further health deterioration, and provide a place to detoxify after exposures received from the outside community. In my estimation, even research is not as crucial as safe housing. After all, it already seems clear that environmental contamination causes illness. Do we have to wait until we know exactly how the body breaks down in laboratory animals before we allow people to live in safe homes?
Family Planning

In some cases, MCS had a profound influence on family planning. For the more than half of the women in Phase II of my study who did not have children, MCS was the reason for their childlessness. Reasons included the inaccessibility of medical offices, poor health, financial problems, and fear of passing on MCS to a child.

Public Access

Being housebound to some degree was a common experience for people with MCS. Some research respondents were able to construct or arrange safe housing, but then felt like prisoners in their homes while trying to avoid outside exposures. Some respondents reported becoming ill from taking walks outside their homes due to outdoor chemicals, such as petrochemical exhausts and pesticides. A number of people reported staying inside to avoid their neighbors’ use of pesticides and herbicides, paints, fabric softeners in dryers, construction chemicals, or other contaminants.

At the time of our study, 8 percent of all respondents were totally housebound. Even if the immediate area around the safe house was safe, venturing into the larger community was risky. Churches, movies, malls, and restaurants were off-limits for many respondents. Almost half of the sample said they were unsafe in any public areas in which perfume was likely to be encountered; and many reported being so sensitive to personal care products that they were unable to have perfumed visitors in their homes. The following comments were fairly typical in regard to public access:

“I am extremely limited, I can drive on unheavily traveled roads with my car air cleaner. I can get myself to the doctor and to food shop. Not much else. I have a recovery period of up to two days after exposure, for example, to perfumes. I have to use a mask, pick times and places very carefully, and be ready to leave or change plans at any time.”

—Forty-seven-year-old woman with MCS for four years

“I have learned I can’t go everywhere I want to go or do everything I want to do so I pick and choose carefully. Before a special outing I rest up for a few days, enjoy the event, then plan a couple of rest days afterwards. I know full well in advance what reactions to expect. I don’t do anything that would result in serious harm. I used to sit at home (afraid to go out), but realized this was only making me worse emotionally and physically. Because of my ‘outings’ there is a little more fatigue—but it’s happy fatigue. I no longer feel trapped or controlled by this illness. I enjoy the quality—not the quantity—of outings.”

—Forty-four-year-old woman with MCS for eight years
Personal Distress

Many respondents reported that they had experienced severe stress and trauma because of the life changes and losses that took place as a result of their chemical sensitivities. Many were living without necessities, such as housing, medical care, and public access. Others had access to necessities, but reported other kinds of losses, such as career advancement, education, travel, hobbies, and community involvement. Further personal distress was reported as a result of the lack of attention and concern for this health problem by the medical profession and the general public. For some, the stresses had become overwhelming. One-fifth of the Phase I respondents had seriously considered suicide, 8 percent had made a suicide plan, and 3 percent had actually attempted it. The following quotations describe severe suffering as a result of severe loss:

“**Toxic chemicals [have] ruined [my] life . . . Plus [losing my] husband, social life, [and] inheritance. I’m going to end up alone in a nursing home with rheumatoid arthritis and chemical sensitivity. All my friends and family are busy with their own lives.”**

—Woman with MCS for thirty-five years

“My dreams have been shattered. Life has merely become a matter of survival, as if I’m in a prison camp. My self-esteem has been damaged due to hostility and ridicule from co-workers and management. I was formerly optimistic and confident in my ability to overcome obstacles. Years of poor health and increasing persistent obstacles have made me sad and bitter . . . the future is bleak. As my health worsens and money continues to dwindle, I fear I will end up with only one option.”

—Thirty-six-year-old man with MCS for six years

Quality of Life Measures

Instruments commonly used to assess the quality of life demonstrated the suffering of respondents in all phases of my study. Note that these are not measures of psychopathology, but variables associated with happiness and fulfillment. We gathered measures of hope, social support, life satisfaction, and disability-induced dysfunction, and the sample scored very low in comparison with people who were sampled in other research.

I think that if any other more “legitimized” group scored this low on any of these variables, it would be cause for great alarm among helpers and researchers. But the MCS population, being invisible and delegitimized, does not draw support. These measures may give you an indication of how much this population is suffering. (Of course, most of you already know that.) And remember, again, these are means (averages) and, as such, obscure the fact that some people actually scored very well on
some or all of the measures. (See Appendix A for published articles and for more detail about the quality of life research.)

Hope

With legitimized illness, such as cancer or diabetes, there is the understanding that it is important for a person to maintain some sense of personal well-being despite the illness. With the aim of extending this concern to MCS, my students and I measured the hope of Phase I respondents. During the study, we used the Herth Hope Scale (HHS) (Herth 1991), which is a respected instrument used to measure hope as an index of well-being. We found that MCS respondents had lower levels of hope than several other populations tested by Kay Herth.

Levels of hope in MCS respondents surpassed the hope level only of elderly widowed people. Interestingly, a higher level of hope was associated with a perceived safer home. This information provides support for the instructions to clean up your home environment (see chapter four). Younger people had lower levels of hope than did older people. Adjusting to the loss of lifetime ambitions and the inability to become financially secure may be more difficult than finding out later in life that you have a disability. (For more detail about the hope study, see Gibson 1999).

Social Support

One important area of study in relation to any chronic health problem is that of social support. We know that for the chronically ill, lower levels of social support are associated with more symptoms and greater mortality. A high level of social support is a good predictor of psychological well-being. Phase I respondents scored lower than healthy people on Part II of the Personal Resource Questionnaire 85 (PRQ85) (Weinert 1987), which measures how much support the test takers feel they have. They scored slightly lower than a sample of women with diabetes who were tested by a fellow researcher, and quite a bit lower than a sample of people with multiple sclerosis. (For more detail about social support, see chapter eleven, and Gibson, Cheavens, and Warren 1998).

Life Satisfaction

During Phase III, we used three popular tests that measure satisfaction with life. MCS respondents scored much lower than did medical outpatients, elderly respondents, and people with other chronic illnesses and handicaps, and residents in all countries except for China. (See Gibson, White, and Rice 1997 for more details.)
The Impact of Illness on Daily Functioning

The Sickness Impact Profile (SIP) (Bergner, Bobbit, Kressel, et al., 1976; Bergner, Bobbitt, Pollard, et al. 1976) looks at respondents’ assessment of the limitations in daily functioning caused by illness. Phase IV respondents’ scores were somewhat alarming in that they were indicative of more dysfunction than is experienced with a large number of other illnesses. MCS respondents had particular trouble in the categories of work, alertness, and recreation and pastimes. Considerable impairment was also shown on the measures for Sleep and Rest, Social Interaction, Home Management, Emotional Behavior, and Mobility. (For more information, see Gibson, Rice, Stables, et al. 1997).

Limitations and Thwarted Goals

The severe limitations and losses that people with MCS often experience are two good reasons for such low scores on quality of life measures. Rippere (1983) showed that people with allergies reported substantial limitation and impairment in their quality of life, and it was expected that people with chemical sensitivities would report even more impairment. We asked Phase I respondents, “Is there any goal or activity that you have really wanted to pursue but haven’t been able to because of chemical sensitivity?” Responses here included the categories of work, education, hobbies, travel, visiting family, and attending church. Remember, access to public buildings is contingent on the ability to tolerate exposure to smoke, petrochemicals, perfumes, and pesticides. Because MCS respondents cannot be near these chemicals without serious health consequences, their work and educational lives are jeopardized.

One-quarter of all participants in Phase I had their education interrupted or denied due to chemical sensitivity. One-third had to discontinue their involvement with their hobbies (e.g., painting) because of their inability to use artistic materials. Others missed travel, socializing, and visiting family. Respondents’ comments were indicative of the severe and even catastrophic impact of coping with their sensitivities. One person wrote, “It has been my ‘goal’ to be self-reliant, but this appears to be impossible.” Another wrote, “I have endured losses and heartbreak to degrees that have nearly devastated me.” Still another said, “I’ve stayed out of (romantic) relationships because I didn’t think anyone would understand my needs. I’ve not had children because of this illness. These have been hard [decisions] to deal with. Sometimes I grieve for the many losses I have had; it never seems to end.”

Clearly, as a group, people with MCS do not have access to the benefits of normal work or social lives. Rippere (1983) pointed out that her respondents (many of whom were allergic to foods) missed out on many occasions that provided others with pleasure and socializing. Chemically sensitive people miss out not only on pleasure, but on the necessities for independent living. When people are unable to work, further their education, or enter public buildings, serious quality-of-life issues are raised. Neurological symptoms, for some, added to people’s isolation and were cause for embarrassment. Although one woman expressed anxiety regarding what others might
think of her, she explained that those who know her well understand her slurred speech, unsteady gait, and lessened cognitive abilities. Cumulative losses of people with MCS were more than most any "normal" person would be able to bear without experiencing severe distress.

"I don't think about goals anymore. For the past thirteen years, I have had hopes that were destroyed. I used to work... I counseled people. I gave up my job, used to direct groups at home, but slowly I couldn't be with people. I moved... and started groups again, but I got sick. I loved cats—had to give them up. I joined groups. I gave that up. Each time my world got smaller, I cried and mourned my loss. Then, I accepted my life and made the best of what I have left. I don't think about tomorrow. I'm grateful for each moment that I survive. I'm overjoyed for each 'good day' when I'm able to accomplish something I want that day."

—A woman with long-term MCS

It is important to understand that personal distress in the face of chronic illness/injury is normal and understandable. (See chapter eight for more about adjusting to chronic illness.) Sometimes goals became simple and survival-related. One person's goal, for example, was "not to get migraine headaches that incapacitate me for days." It may be that for a time your goals will be that basic; but for most people, this is temporary.

Not one respondent in any phase of my research gave up easily. People struggle against insurmountable odds to better themselves. The accusations that those with MCS are experiencing "secondary gain" or somehow "milking the system" are ludicrous when one listens to descriptions of effort and loss as in this account of one woman's attempt to attend college:

"I was diagnosed with chronic fatigue syndrome and again was told it was temporary and to continue with my plans to go to college. My doctors told me I was doing better even though it now took me an entire day to do a half day’s work. I could no longer do yard work or cook meals, thought processing was extremely erratic and I was having difficulty walking. I actually attended one class. The first half was a struggle to keep up with mentally, and the last half was just a blur. Fortunately, I had arranged for someone to pick me up after this class. I was disoriented upon leaving the building and, after walking in circles, finally reached the prearranged place to be picked up. It was extremely difficult for me to accept that not only would I not be going to college, I was unable to do anything else. I knew that I was getting worse, but had so wanted and hoped to make this change I believed the doctors."

—Woman with MCS for eighteen years

Fortunately, almost everyone had some blessings in their lives. Some were almost totally housebound, but had loving and supportive families. Some were ostracized by family, but had found support and strength through helping others. Some could still use
computers; some could leave their homes. People seemed to take, use, and develop whatever resources they could to make some semblance of a reasonable life. Some described riding horses, gardening, writing books, heading support groups or organizations, supporting others with MCS, writing poetry, and starting MCS-related businesses. (See chapter fourteen and Appendix C for further resources along these lines.)

Every aspect of one’s life can be impacted by MCS. For many, the condition is more of a hurricane than a redirecting wind. It takes resourcefulness, patience, and fortitude to confront the challenge of MCS. The remaining chapters in this book are designed to help you with this undertaking.
Chapter Thirteen

Disability Issues

Workplace Accommodations and Applying for Disability Benefits

Facing the reality of not being able to continue working is painfully difficult. Consequently, some people who are very ill with MCS push themselves to continue working much longer than they should, and their bodies often pay the price in increased disability. On the other hand, many chemically sensitive people are forced out of jobs prematurely because of their employers’ refusal to provide appropriate accommodations.

My own bias is that if there is any way of making your work environment safe, remaining in the workforce allows you to keep your income, benefits, work-related self-esteem, contacts with other people, and sense of being productive. Deciding whether you have the option of continuing to work may be easier if you understand something about the Americans with Disabilities Act (ADA).

The Americans with Disabilities Act

The employment provisions of the ADA apply to all employers with fifteen or more employees, including private employers; labor unions; government and nonprofit institutions, departments, and agencies; public transportation systems that receive federal financial assistance; and all public entities that provide public transportation.

Although you are not automatically covered by the ADA just by virtue of having MCS, you may be covered on an individual basis (as with other disabling conditions). To qualify individually, you must meet one of the three prongs of the definition of “handicap” as defined in both Section 504 of the 1973 Rehabilitation Act and the ADA. These prongs are:

1. Having a physical or mental impairment that substantially limits one or more of the major life activities
2. A record of such an impairment, or
3. Being regarded as having such an impairment (ADA 1990, Sec. 3).

Workplace Accommodations for MCS

Although employers sometimes argue that the accommodations required for MCS are so inclusive they are impossible to adhere to, this is usually not true. If you are fortunate enough to have your own individual workspace (office, classroom, etc.), you have many
immediate opportunities to improve the quality of your work environment. You can use an air cleaner, specify less toxic cleaners, and reduce the amount of dust, fresh paper, smoke, and fragrance in your personal workspace. You can also request that no toxic paints, pesticides, or other chemicals be used in your individual office. You can unplug or turn off equipment and lighting that emit electric or magnetic fields if they trigger any symptoms. Changing airflow and heating is more difficult. If your workspace is taking in toxicants from other parts of the building, you may have to ask to relocate your office.

Accommodations may not be as easy to control if you share workspace or common areas with others. In this case, you will have to ask for help with some of the problematic exposures. Air fresheners, for instance, may add unwanted toxic fragrances to bathrooms, but it may not be too difficult to talk employers into using the new citrus-based fresheners once they see how effective they are. Simple baking soda and fragrance-free kitty litter, changed on a regular basis, will also absorb odors. If you want to use alternative air fresheners, you may have to buy the first container and ask your employer to order it from then on. The citrus-based products are sold at most health food stores. Some of the same companies make citrus-based cleaners. If you are sensitive to ammonia, chlorine, or solvent-based cleaners, you may be able to get your office cleaning staff to do a trial with these products or other safe cleaners (see Appendix B for product sources). With paints, you may have to ask for advance warning so you can prepare to be out of the office for a period of time after painting. Or, you can try and arrange that your office use totally safe paints. Milk paints are the least toxic, but hardest to work with, and they do not cover enamels well. It may be easier to convince employers to use some of the lower or no volatile organic compound (VOC) paints (see Appendix B for product sources). Regarding pesticides, you may be able to speak with the person who manages pest control and provide them with information on integrated pest management (IPM). This management system uses the least toxic solutions for bug problems, with toxic applications always used as the last line of defense. Specific suggestions for workplace accommodations are listed on page 234.

The Fragrance Problem

Fragrance on co-workers is a difficult issue. Some co-workers may not be sympathetic to your need for a fragrance-free space in which to work. The least threatening strategy for gaining some cooperation may be to have individual conversations with co-workers. Some people may understand right away when you explain that you become ill from fragrances. However, you must be very clear about what it does to you. Many people interpret a complaint about fragrance to mean that you simply find it irritating. Also, bear in mind that some people wear fragrances because they are attempting to cover up a medical condition, or what they perceive as their own body odor, and they will be uncomfortable disclosing this information. For example, co-workers with bowel or bladder control problems may feel that they are unable to stop wearing fragrance and may be ashamed to tell you why or to discuss alternatives. Explaining that it causes you debilitating symptoms may help. There are many studies that demonstrate the harmful effects of fragrance, and that show how many people in the population complain of
illness caused by perfume. These studies, combined with clippings about some of the fragrance-free sites and activities now in place, may help to convince co-workers that your complaint is justified. The following may be helpful.

**Studies that Find Fragrance Harmful**

- Anderson and Anderson (1998) allowed groups of mice to breathe one of five commercial perfumes for one hour or “zero-grade medical air.” Three of the perfumes caused airflow limitations suggestive of asthmatic-like constriction. All five perfumes caused signs of being toxic to the nerves or nervous tissue (i.e., neurotoxicity) that worsened with repeated exposures. Effects of the perfume varied by dose and included changes in breathing patterns, and indications of neurotoxicity, including altered posture and gait, twitching and tremors, and exaggerated responses to stimuli. Some of the perfume-exposed mice developed limb paralysis and/or convulsions; some lapsed into coma; five mice died. None of the mice in the control group died. Furthermore, air tests found a large number of toxic chemicals in the perfumed air, including benzene-dicarboxylic acid.

- Lorig and Schwartz (1988) found that fragrance alters the human electroencephalogram (EEG) pattern, and that similar fragrances can have very different patterns. The effects from nose breathing were greater than those from mouth breathing. And, fragrance levels in room air were able to stimulate the nervous system, thus affecting EEG patterns, even when fragrance was not detectable through odor.

**Fragrance-Free Organizations**

- The University of Minnesota School of Social Work became fragrance-free in 1997. Both faculty and students who enter the building are asked to wear no fragrance.

- The National Women’s Studies Association’s annual meeting has been completely fragrance-free since 1997.

- The Association for Women in Psychology’s annual meetings have been fragrance-free since 1997.

- The executive committee of Division 35 (Psychology of Women) of the American Psychological Association has had fragrance-free meetings since 1996.

**How to Request Accommodations**

To begin, you may decide to informally ask your immediate supervisor for the accommodations that you feel would help you to function safely and productively in the workplace. You can provide physicians’ letters and explain your problem to the best of
your ability. If your documentation can state that you are sensitive to—or become ill from—chemicals, and that it threatens your health to be exposed to them, this will be helpful. These letters should be tactful, tasteful, and not reveal too much personal information. You need to maintain your dignity at work. (For example, giving your employer a letter stating that you have toxic encephalopathy, which means brain damage, may not be exactly what you want your documentation to say.) The letter also should be tailored to you as an individual. Some physicians, for instance, use form letters that may request MCS office accommodations to include products that may be a problem for you (e.g., vinegar).

It is best to put your request in writing. Your employer is not required to provide any accommodations if you do not request them. If you encounter resistance to getting the accommodations that you need, you will need to speak with those who have more authority until you receive help. Depending on the structure of your workplace, you may save a lot of time and energy by speaking to someone with a lot of authority right at the start. At the least, you need to talk to someone who has enough authority to implement changes once convinced to do so.

You can also write a “Request for Reasonable Accommodation.” This legal document states that you have a disability covered by ADA, and that: “In accordance with Title II of the Americans with Disabilities Act and section 504 of the Education Act, I am in need of the following accommodations for my disability in order to be safe working in . . .”

You can then list your needed accommodations. Be judicious, however, and ask only for what you really need so as not to be interpreted as asking for the impossible. Toni Temple (see activist profile in chapter fourteen) reminds people with MCS that it is important to be reasonable in requesting accommodations. Remember that employers are not required legally to make expensive renovations. An employer does not have to make an accommodation that imposes an “undue hardship” on the operation of the business. 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.

Although you may be unable to perform some minor functions of your job, you must be able to perform its “essential functions” to qualify for ADA accommodations. If you are a typist, for example, and sustain an injury that renders you unable to type at all, then you are unable to perform the essential function of your job and your employer does not need to modify your job for you. However, if you are unable to stand over the photocopy machine, and this is a minor part of your job, then your employer must accommodate your need.

Many MCS accommodations can be made easily and with little expense. Limiting smoke and perfume in the workplace is not costly or difficult. Using less toxic air fresheners or paints, likewise, is not cost-prohibitive. Providing an air cleaner for employees is also a reasonable strategy that is fairly easy to implement. The booklet
Multiple Chemical Sensitivities at Work: A Training Workbook for Working People by the Labor Institute (1993) is a helpful workbook that details possible interventions for MCS. You can purchase it to give to your employer. Although some suggestions for accommodations are listed below, the booklet may lend credibility to your request.

Once you receive cooperation, looking ahead to prevent future mishaps is critical. If you know that some process, such as painting or spraying, is being considered, finding out when it will be done and what chemicals will be used may save you from another toxic insult.

**Specific Workplace Accommodations That May Be Helpful in MCS**

1. Work near a window that opens rather than in a sealed area of a building.
2. Reduce the fragrance that co-workers use if possible.
3. Eliminate the use of toxic pesticides and implement the substitution of less toxic alternatives, such as boric acid for ants and roaches.
4. Initiate flexible work hours that allow you to leave during highly toxic exposures, e.g., painting, and/or to work during off-hours to avoid photocopy and other office fumes, and rush hour traffic.
5. Receive notification of impending pestciding, painting, and construction/repair that may generate fumes or cause other harmful effects.
6. Eliminate “air freshener” in bathrooms, install fans, open windows, or use nontoxic alternatives.
7. Relocate your work area to a safer part of the building.
8. Place an air cleaner in your work area.
9. Vent the photocopy machine appropriately.
10. Use less toxic cleaners and eliminate strong smelling ammonia, solvent, phenol, or chlorine-based solutions.
11. Delegate errands to toxic areas, photocopying, and other small nonessential tasks to an employee who does not have chemical sensitivities.
12. Minimize the amount of time spent under fluorescent lights or in the vicinity of any transformers, electric cable, computers, or other electromagnetic field sources that trigger symptoms.

**Applying for Disability: Receiving Assistance When You Can No Longer Work**

It is possible that regardless of how hard you attempt to “hang on,” you may reach a point when you are no longer able to work. This may be temporary or permanent, but unless you are independently wealthy, you may find yourself in the position of having to apply for disability compensation. There are several types of disability compensation available, including private disability insurance (if you have a policy), the Social Security Administration’s Disability Income and Supplementary Security Income, and workers’ compensation.
Private Insurance

In addition to health insurance, many employers offer disability insurance for a modest fee. If you have the opportunity to purchase this insurance, it can be an excellent investment. Read the policy carefully to be sure that no conditions that resemble MCS are excluded. If the policy does not exclude MCS, purchase the highest level of coverage possible. Some policies allow you to choose a premium based on what portion of your current salary would be paid to you monthly should you become disabled.

Having disability insurance does not mean that the insurance company will not try to avoid payment. Private insurers have access to the same detractors who testify for employers against people applying for any other types of compensation for MCS. However, purchase of the insurance (along with excellent medical records and documentation of symptoms experienced at work) will lay the groundwork for future benefits should you ever become disabled. If your employer does not offer disability insurance, you may be able to purchase it privately.

Social Security Administration Benefits

The Social Security Administration (SSA) provides Social Security Disability Income (SSDI) for people who are disabled to the point of being unable to work. The two and a half million people who apply to the SSA each year for disability benefits must deal with the state agencies called Disability Determination Services (DDS). The DDS conducts disability determinations for the SSA. Disability Insurance (DI) and Supplemental Security Income (SSI) are the two major benefit programs for people with disabilities. These two programs define disability as “the inability to engage in any substantial gainful activity by reason of a severe physical or mental impairment that is medically determinable and is expected to last at least twelve months or result in death.”

Established in 1956 by Title II of the Social Security Act, SSDI provides monthly cash payments to severely disabled workers. Similarly, SSI, which was established by Title XVI in 1972, provides monthly cash payments to aged, blind, or disabled people whose financial resources are below a required threshold.

Qualifying for Benefits

You do not have to be completely and totally disabled to qualify for SSDI, only unable to engage in paid work. But apply as soon as possible after you become disabled. It takes at least sixty to ninety days to process your initial claim. The qualifying process involves filing an application and supporting documentation through a local field office that then forwards the materials to a state Disability Determination Services (DDS) office.

A DDS examiner then works with a medical or psychological consultant to study your documentation to make a determination. Additional data may be requested. (Note: At this level the applicant does not have any personal contact with any of these
professionals.) If the application is denied, the applicant can ask DDS to reconsider. A new examiner/consultant team then reviews the application. If your application is denied a second time, the next step is an appeal to an Administrative Law Judge (ALJ) in the SSA Office of Hearings who will hold a hearing where the applicant can testify and present new evidence. If denied at this level, the applicant can appeal to SSA’s Appeals Council and then bring suit in federal court.

The SSA is supposed to use the following five-step sequential evaluation process to determine whether an applicant qualifies for benefits:

1. Is the applicant engaging in substantial gainful activity? (The answer must be “no.”)

2. Does the applicant have an impairment that has more than a minimal effect on the applicant’s ability to perform basic work tasks? (The impairment must be expected to last twelve months or result in death.)

3. Does the applicant’s impairment meet or equal the medical criteria for an impairment in SSA’s listing of impairments? (This list includes over 150 categories presumed to meet the severity test. You can bet that MCS is not on it.) If the impairment is not listed or the condition does not match listed criteria, then it 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. (Some conditions, however, must be assessed by functional limitation, e.g., musculoskeletal conditions. But awards for musculoskeletal conditions are infrequent. MCS falls into the category of impairment that is difficult to document by medical fact, and therefore proving functional limitation is crucial.)

4. Comparing the applicant’s Residual Functional Capacity (RFC) with the physical and mental demands of the applicant’s past work, can the applicant perform his or her past work? If medical evidence does not substantiate a condition of adequate severity in SSA listings, the adjudicator must determine what the applicant can still do in a work setting. The examiners must use “all relevant medical and nonmedical evidence,” such as statements from others about the applicant’s symptoms. If it is determined that the applicant can still perform past work, the claim is denied.

5. Can the applicant perform other work in the national economy? This is determined using the RFC, age, and educational and skill level of the applicant.

The application process is standard, but leaves room for complex decision making by the adjudicators. For example, if the person cannot be deemed disabled on the basis of medical evidence only, the adjudicator must then decide if the applicant can perform prior or other available work despite their condition. The SSA’s medical vocational rules suggest that older, less educated, and less skilled people are more likely to be given
benefits. (See discussion of this process later in this chapter under “Is the Application Process Fair?”

**Workers’ Compensation**

Workers’ compensation is a system of insurance to which employers contribute money to cover wages and financial damages for those injured on the job. In exchange, workers’ compensation laws protect some employers from lawsuits by employees. Employees who are eligible for workers’ compensation are not able to sue their employers for a greater benefit. However, they are able to sue other parties, such as architects, manufacturers, and building owners. In addition, there are some exceptions to employers’ protection. If employers are also the building owners, they are not protected from lawsuits. If they intentionally expose workers to unsafe conditions (they do not have to have intended harm), or if the illness would not normally be expected as a result of that employment (e.g., toxic exposure is not expected in offices), then the employer is not protected from lawsuits. Your workplace has the forms you need to file for workers’ compensation if you believe you were chemically injured on the job.

**MCS and Disability Compensation**

Dubin cites two legal cases where disability benefits were awarded for MCS and three cases where they were denied. Dubin cites Slocum v. Califano as one of the first cases in which disability under the Social Security Act was awarded for MCS. The plaintiff had to live an isolated chemical-free lifestyle and was debilitated for days following simple chemical exposures. In this case, benefits were awarded and were retroactive to the onset of the sensitivities some ten years earlier (Dubin 1994). In Kouril v. Bowen, a woman was granted disability benefits on appeal because of the “disabling effect” of ordinary chemicals and the combined effect of her many health problems. The court cited the standard requiring that a person be “unable to engage in substantial gainful activity,” and reiterated that total incapacity is not required to acquire disability compensation (cited in Dubin, p. 13). The three denied cases that Dubin cites all involve court skepticism regarding medical evidence of disability acquired through “environmental” medicine.

We sent an additional questionnaire to those who indicated in Phase I that they had applied for disability compensation for MCS, that asked about the conditions under which people became disabled, diagnoses used in filing the application, and the responses of the courts to their petitions. For more information, see Appendix A, “Research Methodology.”

**Stresses of the Application Process**

The application process is extremely stressful, as applicants must often face skeptical examiners with unsafe offices and struggle to maintain their self-esteem despite acquiring incorrect and stigmatizing psychiatric labels. They must also endure severe
financial problems during the waiting process, and come to terms with a new self-definition that does not include work. How could it not be stressful under such conditions? According to respondents, the most difficult parts of the application process are the appointments with Social Security Administration (SSA)–appointed medical examiners. These appointments are challenging because SSA office environments are rarely safe and skeptical examiners seldom know anything about MCS.

People often are humiliated and frustrated by psychiatric labels that render their physically caused complaints invisible and invalid. Interestingly, psychiatric labels can be assigned at any point in the application process, even if the applicant’s personal physicians provided only physically based diagnoses. For example, only seventeen people in my study filed for disability with a psychiatric diagnosis included in their petition (either in combination with MCS or as a stand-alone classification). Twenty-seven, however, were granted disability benefits for psychiatric reasons. When an SSA-chosen expert assigns a psychiatric diagnosis, this diagnosis can be used for disability eligibility even if none of the applicant’s personal health providers believe the applicant has a psychiatric diagnosis. For example, one woman filed for disability for chronic fatigue syndrome (CFS) and was granted disability for paranoid schizophrenia.

Some people choose to allow the use of psychiatric diagnoses in filing because of their financial desperation. One woman decided to “accept a psychiatrist diagnosis rather than starve” and gained benefits on her first attempt. Likewise, another woman who had endured a long wait for benefits chose to cope with adjusting to a psychiatric diagnosis rather than fight to prove physiological impairment. She says, “It took one and a half years to accomplish my being granted disability benefits, during which time I became homeless due to no employment, no income, and depleting my savings.”

One woman who successfully acquired Social Security Disability Income and work insurance (but not workers’ compensation) after filing three times for Social Security benefits, four times for workers’ compensation, and three times for work disability, describes the process as:

“Worst fight of my life. Pure hell. I gave into PTSS [posttraumatic stress syndrome] as it was the only way to get disability. . . . We have spent over $200,000 getting medical care and diagnosis for disability. Became homeless . . . My husband was under such pressure fighting for my rights that he had a heart attack and double bypass.”

—Twenty-four-year-old woman with MCS for one year

Not every applicant knows what diagnosis is used to determine disability. Some only know that the Social Security Administration has “determined them to be disabled.” MCS was not the only reason for discrimination in the application process. One woman said she was finally granted Supplemental Security Disability Income after five applications in a ten-year period because she was “too old to fill scarce job slots.” Physicians did no
laboratory tests, documentation was scarce, and on each new application, she was sent to a psychiatrist. Legal Aid had refused to help.

Because of lack of income, many disability applicants live with their parents or extended family during the application process and risk further health decline because of the chemicals in the home environment. Some applicants have no permanent place to live, and survive on porches or in recreational vehicles or cars.

**Documenting Invisible Disabilities**

The challenges of proving an invisible disability are considerable, especially because “not looking sick” may prevent the MCS applicant from receiving consideration or from being seen as needing help. It is a frustrating fact that people can be more sympathetic when your handicap is more obvious. Nonetheless, in a court situation, you have the difficult task of convincing a judge about the reality of your invisible health condition.

Respondents used some of the following strategies to help them legally prove the reality of MCS. Some people recorded their symptoms through detailed written descriptions of their reactions. One woman sent a videotape to the judge who was deciding her case that was recorded while she was experiencing a chemical reaction. Another individual who had been denied benefits after three appeals had friends and neighbors testify as to her decline in health since becoming chemically sensitive. This same woman also provided the judge with photographs of her safe bedroom and car with air filters. One respondent even reported having had a life-threatening reaction while she was in court, which convinced the administrative law judge (ALJ) that she really was ill.

However you choose to document your symptoms, it needs to be concrete and detailed enough to help a judge understand that chemical exposures lead to disabling symptoms. One woman with MSC explains:

“[It is] best to explain, in detail, how you are disabled, i.e., ‘when I am around perfume I get dizzy and lose my memory and sometimes lose coordination,’ etc. They usually deny first claim[s] and insist you can find a place to work [that] is ‘safe.’ You must reply why it is not safe for you, how you have no control over what others wear and use, etc. List each item and what it does to you in detail….”

You might want to make a list of the chemicals you are exposed to in a normal working day, including the identification, severity, and duration of each symptom caused by the chemical reaction. You can make the case that you cannot control exposures in the workplace—they are inevitable. And cumulatively, the symptoms you are exposed to at work keep you debilitated to the point that it is impossible for you to function.

The level of persistence needed is sometimes astounding:
“Getting disability and work[ers’] compensation benefits while suffering from MCS-related pain has only been obtainable through tenacious persistence. They (workers’ comp and the private carrier) will stop benefits and will only be persuaded by well-organized appeals.”

—Forty-one-year-old woman with MCS for six years

In a sense, it is a full-time job just to apply for benefits, and the effort must be seen in context of your long-term health and survival. The process will require collecting extensive medical documentation, educating Social Security Disability Income (SSDI) officials and examiners, and making numerous phone calls. Some people even contacted their state senators for assistance. It is very difficult to do this type of work while you are feeling poorly, but even if there is no one to help in the process, you must find a way to get it done.

**Physician Assistance**

Obtaining documentation from physicians regarding your MCS may be the most important component of the disability application process. It is essential that the documentation be from doctors who are knowledgeable about and supportive of chemical sensitivity. Being certain that your physicians will testify or provide written statements for a hearing is also important. Of course, this in itself is a hardship for people with MCS, as their medical needs are often reported to be unmet (Engel, Gibson, Adler, et al. 1996). In addition to the difficulties of finding physicians who are educated about MCS, you have the added obstacle of coping with their office environment. Nonetheless, reports from physicians are extremely important. Be sure to review any physician reports before they are submitted. Even with excellent documentation, it will be challenging to win MCS-related disability cases.

**Be aware:** Documentation varies widely. Well-documented physician reports must include some general MCS education as well as a statement that the applicant is disabled to the point of being unable to engage in substantial gainful activity. On the other hand, there are some reports that even a sympathetic judge would not take seriously. For example, in one instance, a physician scratched two sentences on a prescription pad something along the order of: “Please grant disability to. She can hardly walk from place to place let alone work.” Needless to say, this woman was not granted benefits.

A physician’s letter needs to be serious. It should be written or typed on professional letterhead and detail the reasons why you should be considered for disability benefits. I suggest that you explore this issue when you first begin seeing a physician, even if you are not currently disabled. Ask the physician what they would do to help you if you ever become disabled, and what type of documentation/report would be submitted. Knowing ahead of time that your physician would desert you when you needed their assistance can save a lot of heartache. There are physicians (even MCS experts) who want no part...
of the disability application process. One physician told her patient that she would no
longer be able to treat him if he went on disability.

At the very least, your physician needs to be aware of the process used by the Social
Security Administration (SSA) in determining disability, particularly regarding the
emphasis on functional capacity. If your medical documentation can explain in detail
what you can and cannot do, and how your ability to work is compromised by chemical
exposures in the workplace (and that these chemical exposures are in every
workplace), this will help the Disability Determination Services worker to see that your
Residual Functional Capacity is low.

The Single Photon Emission Computed Tomography (SPECT) is one medical screening
procedure admissible in court and it shows objective evidence of physical brain
damage. Although this procedure is expensive and difficult to obtain because so few
practitioners use it for MCS, some applicants (particularly those who have had one
massive exposure likely to cause neurological damage) have sought it out to cut
through some of the medical denial.

Is the Application Process Fair?

A recent report by the General Accounting Office (GAO) (1997) suggests that the
process of determining disability qualification has not been fair. For example, the report
found that 65 percent of those who apply for Social Security Disability each year are
denied. One-third of these appeal to an administrative law judge (ALJ), and two-thirds of
these eventually get benefits. Overall, approximately 49 percent of those who apply
receive benefits; 71 percent of awards are made at the initial determinations or
reconsiderations and 29 percent are made on appeal. The differences between the
likelihood of being awarded benefits at the initial determinations (by DDS) and at the
ALJ level has brought the Social Security Administration (SSA) under scrutiny both from
within and outside of the organization. The Government Accounting Office report
explored the fact that ALJs are more likely to grant benefits. Although ALJs work for the
SSA, safeguards protect their independence. For example, SSA management does not
control their pay or subject them to performance appraisals. This independence allows
ALJs to reverse decisions made by DDS without retribution. According to the
Government Accounting Office (1997) report, the following four reasons account for the
discrepancy in benefit awards granted by the DDS and ALJs:

1. Residual Functional Capacity (RFC) is often assessed differently, with ALJs finding
many more people to have severe limitations in the workplace. The classification
that the person’s RFC is “less than the range of sedentary work” often leads to
receiving benefits. ALJs rated 66 percent of cases as such while DDS saw less than
6 percent of applicants as fitting this category.

2. Although the DDS has medical or psychological consultants determine RFC, an ALJ
may or may not respect these findings, and has the authority to determine RFC
independently. ALJs may request that an Independent Medical Examiner (IME) see an applicant, but they rarely do. IMEs were involved in only 8 percent of cases in which benefits were awarded at the ALJ level. (This has probably worked in favor of those with MCS.)

3. The reasons for denial at the DDS level are often not clearly explained in the paperwork given to the ALJ. This encourages the ALJ to start from scratch in making a determination. This probably works in favor of those with MCS also, but is targeted for change as part of SSA’s attempt to make the process more congruent at the two levels. SSA plans to require that reasons for denial be clearly indicated so that they can be better used as “a solid foundation for subsequent appeals.” (This will likely make it more difficult for people with MCS to obtain benefits at the ALJ level.)

4. New evidence can be presented at the ALJ level and in approximately 75 percent of the appealed cases it is. The ALJ level is the first opportunity applicants have to testify in person as to their impairment, and this personal testimony allows the ALJ to judge the person’s credibility. (This probably works in favor of most MCS applicants.) Applicants also may engage the services of an attorney at this stage, and attorneys are financially motivated to obtain awards. In addition, 10 percent of people applying for benefits switch to a mental/psychological diagnosis for the hearing.

According to the General Accounting Office report the disability determination process has been under scrutiny since 1994 with SSA aiming to “make the right decision the first time,” thus saving time and money.

Some of the planned changes include more clearly indicating any reasons for denials, sending a number of applications back to DDS rather than ALJs for appeal, and encouraging ALJs to engage the services of independent medical examiners. In fact, a 1996 ruling reinstates a policy that an ALJ must use “expert medical opinion” in demonstrating that cases that do not match disorders on their lists are actually equivalent in severity. None of these changes will help those with MCS. However, the SSA plan to conduct a “predecision interview” with a disability examiner before rejecting an application will give the MCS applicant the opportunity to speak to someone in person.

**Medical Evidence and Opinion**

Adjudicators must determine disability from medical opinion and evidence. Medical opinion may be gathered from physicians or psychologists who have ongoing relationships with the applicant, clinics or others who have treated the applicant shorter term, and consultants. Medical evidence can include medical history, clinical examination findings, laboratory test findings, diagnostic statements of disease based on signs and symptoms, and treatment suggestions and prognoses (expectations as to probability of improvement). Statements from physicians as to what the person can do in the workplace are also needed as medical evidence. These statements should detail
the person’s limitations for performing workplace tasks, interacting with co-workers, understanding and carrying out instructions, and stamina for workplace stress.

One important issue to consider is the weight that is accorded to medical opinions, especially given that MCS and those who treat it get very little institutional respect. The SSA is supposed to consider the following factors when deciding what weight to give a medical opinion:

1. More weight is to be given to a physician who examined the patient than to one who didn’t. (Therefore, avoiding hostile examiners is very important, because the fact that they saw you will give their testimony more weight.)

2. A physician who has a treating relationship should be given “controlling” weight, if the opinion is well supported by the documentation (i.e., consistent with the medical evidence).

3. Weight given should be commensurate with the length of relationship, number of medical visits, and extent of examinations and testing performed or ordered by the physician. (See your physician regularly and leave an appropriate paper trail, if possible.)

4. An opinion is given more weight if it is supported by evidence (e.g., lab tests) and is clearly explained.

5. Consistency with the case record should give an opinion more weight.

6. Specialists must be given more weight in their area of specialization.

Adjudicators must evaluate whether your condition could produce the symptoms you describe. For this task, you can submit statements from family, employers, and others in addition to medical evidence. Adjudicators are not supposed to reject a claim simply because the medical evidence does not clearly support your statements. To evaluate your pain and other symptoms, they should consider what factors aggravate pain and symptoms, what medications are used and their side effects, treatments used, and other factors. For MCS, you can see that, theoretically, it should be possible to gather statements from others, explain that symptoms are aggravated by unavoidable exposures in the workplace, document that medications are difficult to use due to sensitivities, and educate the examiner that treatment involves no exposures. This seems logical, but requires reasonable documentation from physicians, which generally has not been available to those with MCS.

It is important to understand that the reality of remaining on disability benefits long-term is an ongoing process and is not ever a “done deal.” In fact, remaining on disability compensation may require periodic reviews when you will be required to demonstrate that you still are unable to work. Reviews often mean entering toxic offices, facing
skeptical examiners, having expensive testing, and a renewed bout of stress, much as in the original application process.

**Beyond Disability: Damage Suits**

You may decide that your workplace was instrumental in robbing you of your ability to support yourself, and therefore you may decide to file a lawsuit for further compensation. You will need to find out the statute of limitations regarding toxic exposures in your state. If the claim is a workers’ compensation claim, it must be filed within twelve months of the incident, or within twelve months of the time that you found out the incident was responsible for your negative health consequences. You must notify your employer’s insurer within thirty days of the incident. Without this notice, there is no case. Therefore, Baiz (1997) suggests that you use a written notice with return receipt requested.

If the incident is not a onetime exposure, but rather an extended repeated series of exposures, then occupational disease laws may be more appropriate than workers’ compensation, which is for work-related accidents. Baiz says that under the Occupational Disease Act, you must file a claim to your employer, its insurer, or the Department of Labor within two years from the date you knew or should have known that your disability resulted from an occupational disease. In the event that death results, your beneficiaries have one year to file a claim.

With legal advice and help, toxic tort lawsuits can be filed on a variety of bases. Although success depends on a wide number of factors (locale, attorney, judge, jury, your documentation), Plunkett (1993) shows that there are a number of ways that legal theory supports gaining compensation for workplace-engendered MCS. She reports that most states have had plaintiffs win cases for sick building syndrome or MCS on the basis of negligence, strict liability, breach of contract, express or implied warranties, and fraud and misrepresentation. Each is mentioned here, not as legal advice, but to allow you to assess whether you would like to consider the matter with an informed attorney.

**Negligence**

Negligence is failing to exercise the level of care that a reasonable person would exercise to protect others against unreasonable risk of harm. Personal injury cases from indoor air pollution are often based on negligence. Proving negligence requires that the defendant owed a “duty of care” to the plaintiff, that the duty had been breached, and that the breach resulted in harm.

**Strict Liability**

Strict liability refers to liability for damage from a dangerous activity, and does not require negligence as a factor. In strict liability, reasonable care could not have eliminated the risks. For example, products that are dangerous by manufacture or
design are often the targets of indoor air pollution lawsuits. Plunkett (1993) says that to succeed, a plaintiff “must demonstrate that he or she was injured by a defective product which was unreasonably dangerous because of its manufacture, design, or lack of warning” (p. 9). Strict liability applies to manufacturers, engineers, architects, contractors, and others, and can be targeted at heating systems, glues, photocopy chemicals, and any other toxic materials to which people are exposed in the workplace.

**Breach of Contract**

Breach of contract and express or implied warranties can be between builders or sellers of homes/buildings and buyers. Express warranty is a representation to a buyer whether in written, verbal, or other form. Injuries from indoor air pollution may be result of breach of warranty because sold items are implied by law to have the warranties of merchantability and of habitability. That is, they are fit to be sold, and fit to be used for the purpose for which they are sold (e.g., homes are meant to be lived in). If carpets emit noxious fumes or mobile homes have unsafe levels of formaldehyde, then the warranties of merchantability and habitability have been breached. Plunkett (1993) cites a case where a family was granted $16,203,000 from urea formaldehyde particleboard manufacturers because of the breach of the implied warranty of merchantability. The family was able to prove that:

1. The formaldehyde levels in the home were beyond recommended limits.
2. The particle board was the source of the formaldehyde.
3. Serious health effects had resulted.

The warranty of habitability requires that severe damages occur—a home may not merely be an irritant. Although it is more difficult to successfully sue over habitability for commercial buildings, many argue that commercial buildings also fall under the warranty of habitability.

**Fraud and Misrepresentation**

Misrepresentation involves false statements—either fraudulent or innocent—by builders, sellers, or brokers. It is more difficult to prove fraudulent misrepresentation, as you must prove that the defendant knowingly made a false statement with the intent of getting you to rely on it, and that damage ensued to you as a result.

**Other Legal Theories**

Plunkett (1993) mentions other legal theories that may be used to recover damages for MCS, but which are pretty much untested in indoor air pollution cases. One is nuisance, which involves interference with or invasion of property. Nuisance cannot be used simply for personal injury, but it may be combined with negligence or strict liability. Under risk of future illness, a plaintiff may be able to recover damages for the increased risk of future illness as a result of a toxic exposure, but there must be some
demonstrable damage present. For example, a person hospitalized for smoke inhalation following a chemical fire may then argue that they are at greater risk for lung disease. Even fear of future illness as a result of toxic exposure may be used in toxic tort litigation, and Plunkett cites several successful cases. Plunkett also says that battery might also be used in cases of toxic tort, although there are no known cases. Battery requires that the defendant intentionally caused harmful or offensive contact and that the contact occurred. Contact with a toxin can in and of itself constitute the injury. Contact with asbestos dust, radiation, and other toxins has been the subject of a large number of lawsuits. Plunkett says that battery may be easier to prove than negligence because battery places less emphasis on causation.

**Documentation**

To solidly document personal injury claims, Baiz (1997) advises the plaintiff to keep good records, including finding out as much as possible about the exposure, and keep a journal of symptoms, medical appointments, consultations, and therapy. He advises noting mental/emotional symptoms as well as symptoms more often thought of as physical. If there are witnesses to the exposure and the effects it had on you, provide names and addresses.

Although damage suits can consume tremendous resources on your part and be terribly stressful to initiate, they have the potential to put polluters on notice, and to prove that checks and balances sometimes actually work. Damage suits set precedents, making it easier for others who are injured by toxins to receive compensation, gain publicity for the issue of a safe workplace, and, if successful, provide you with compensation for some of what you have lost.

**Applying for Disability Benefits**

The decision of whether to apply for disability compensation is an extremely difficult one. On the one hand you have the difficulty of the process, and if adequate accommodations in your workplace can be made, it may be more beneficial to continue working. However, if your workplace is forcing you deeper and deeper into illness, then it may be necessary to receive benefits so that you can give your body the rest it needs. This area is so new, and interpretation of policy is in such flux, that little is certain about what will really work in the application process. Talk to other people who have applied for disability and determine what helped and what challenges they faced in the process. You can also gather any resources they may have that might help you. See Appendix A for some more information about the application experience of my research respondents. It may be less stressful if someone helps you through the process, and that person need not be an attorney. Many applicants have acquired benefits without legal representation. This legal arena may heat up in the next few years given that
Corporate interests already are attempting to exclude MCS from being covered by the Americans with Disabilities Act (ADA). The issue of compensation for damage by chemicals in a chemical-dependent economy cuts right to the heart of economic justice, power, productivity, and cultural issues.

For some, acquiring disability compensation is a step toward increased rather than decreased productivity. (See chapter fourteen.) Some people unable to work in traditional contexts have gone on to found organizations, edit newsletters, write books, support others, and foster important political and social change.
References


Environmental Accessibility

By Melanie Lyle

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Human Ecology Action League, Inc.
P. O. Box 29629, Atlanta, GA 30359-0629;
404-248-1898
HEALNatnl@aol.com
http://members.aol.com/HEALNatnl/index.html
Environmental Accessibility
By Melanie Lyle

In 1999, I requested and was granted a meeting with five department heads, including
the Vice-Chancellor, at the university where I am enrolled. It was a meeting that I
needed oxygen, a ceramic mask, and a personal ionizer to attend. Its purpose was to
discuss how I might gain access to the university so I could take some hybrid classes at
home and on campus. When asked how I was going to accomplish this in light of my
chemical sensitivities, I had to admit that the logistics seemed intimidating. And there
were no answers offered. Although the university officials appeared sympathetic and
accepting of my disability, the burden of environmental accessibility seemed entirely
dependent on my resourcefulness and not on the institution's cleaning up its indoor air
quality.

Environmental accessibility to public buildings, facilities, and transportation for people
with MCS and related sensitivities is not a new issue. But I realized as a result of that
meeting that every one of us affected by environmental health issues is in a position to
be a useful voice in our respective communities. But how do you go about making your
community aware of the need for environmental accessibility? What makes a public
building environmentally accessible? What really is environmental accessibility?

WHAT IS ENVIRONMENTAL ACCESSIBILITY?

Simply put, to a person with chemical sensitivities, environmental accessibility means
that he or she can gain access to and remain in a public facility or building without
compromise or damage to his or her health.

Environmental access regulations should require that public buildings and facilities be
ventilated to “eliminate, separate, and filter out” existing pollutants, that the introduction
of pollutants be reduced by employing effective indoor air quality control techniques,
and that proper environmental construction techniques and choices of furnishings be
employed in new buildings to ensure good indoor air quality (IAQ).

Without environmental accessibility, much of the world beyond our safe homes remains
totally inaccessible for some people with MCS. For others, it extremely limits what the
preamble for the ADA Guide for Small Towns calls our “participation in the mainstream
of public life offered to all Americans.” In order to gain that access it is necessary to
consider what strategies and tools we can use in the very cities and towns where we
live. But how to start? With a pre-existing legal tool? With a grassroots effort? Let’s
consider the legal tool first.
THE ADA, THE ABA, AND THE ACCESS BOARD: THE LEGAL TOOL

Though it can be daunting, start by making yourself acquainted with existing disability access regulations, guidelines, and regulatory agencies. There are federal, state, and local laws that may apply. You need to find out what they are. At present, however, it is rare to find mention of MCS-related concerns specifically addressed in these documents or by these entities.

The Americans with Disabilities Act (ADA) provides a number of regulatory procedures and precedents for those with disabilities. Specific to persons with MCS who are concerned about disabilities, Title III of that act deals with “covering public accommodations and commercial facilities.” The ADA Title III Technical Assistance Manual lists the regulations for accessibility. It is exactly 105 pages and can be downloaded off the Internet for free. You will find, however, that the document primarily addresses disabilities such as physical mobility, blindness, or deafness, rather than “emerging” disabilities such as MCS. Check the "Resources" list that accompanies this article for the ADA Web site and information line numbers.

The Architectural Barriers Act of 1968 (ABA) addresses access to “facilities designed, altered, built, or leased with Federal funds.” The difference between the ADA Accessibility Guidelines (ADAAG) and the ABA Guidelines is that the “ADAAG cover the construction and alteration of facilities in the private sector (places of public accommodation and commercial facilities) and the public sector (state and local government facilities). The accessibility guidelines for ABA primarily address facilities in the federal sector and others designed, built, altered, or leased with federal funds. Both of these regulatory tools are overseen by the Access Board.…

These are the legal tools at your disposal should you encounter an environmental access challenge in your city or town. And owing to the depth of each of these documents it’s also possible that you may need legal help just to interpret the law correctly and make it work for your particular case. As a start, some information is available from the Department of Justice (DOJ). See the DOJ listings in “Resources.”

Also check state and local laws. You may find some provisions that will be helpful.

THE GRASSROOTS APPROACH: A PUBLIC BUILDINGS RATING CHECKLIST

The other avenue to access is a grassroots alternative. A grassroots approach means local action for local problems and involves bringing a situation to the attention of the people who can do something to change it. In the case of access, this can be accomplished by devising a checklist and rating the accessibility of a community’s public buildings for people with MCS and then making the information available to building owners and managers.

Start by doing your homework. Find out the building codes and zoning regulations in your town or city. The Department of Justice oversees the certification of State and local
building codes. You can find information about the building codes in your area on the Web at http://usdoj.gov/crt/ada/certcode.htm. The certification process relies on voluntary compliance and local inspection. For instance, when business owners are building, they are dependent on what’s already documented in the building codes. By requiring that buildings be certified in compliance with the codes, this documentation tries to make accessibility part of the building process rather than an afterthought. It’s important to be aware of this when you approach building owners or managers with your checklist. They may at first be a bit confused, because they believe they are in compliance and, from their perspective, have gone through a pretty rigorous process and maybe even some additional construction expense to get there.

When gathering your information, you should create a master checklist and take it with you whenever you go out. A sample checklist might include items such as the following: smoke-free access to walkways, through hallways, and under outside air intakes; no deodorizing devices in public restrooms or other common areas; notifications posted for remodeling activities, along with lists of chemicals used; curb cuts and ramps for easy transport of oxygen to and from an access area; fragrance-free soaps in the public washrooms, etc. You might find it helpful to categorize your list so you can expand it.

The following example of a troubleshooting list for rating public places provides a good place to start, until you feel comfortable designing your own:

1. Make three categories: Permanent Features, Renewed Features, and Occasional Features.

2. Then allow a “response” column for each.

3. “Permanent Features” includes items such as “carpeting” and “parking lot next to air intake,” because these features would most likely be changed only upon need for replacement (carpet) or perhaps never, in the case of the parking lot location.

4. Examples of “Renewed Features” include pesticides used, air fresheners, cleaning products, any items where your “response” might be to “suggest less toxic alternatives.”

5. “Occasional Features” include renovations and major pesticide applications, with your “response” being to “require notification at entry point.”

Next, make a list of the public places in your town to which you want access. Do a preliminary canvas by phone, if you can, to see which ones are smoke-free and which ones aren’t. If you are unable to do this, ask a friend or family member to help. Then, if you are able to go out, make short trips to each of these establishments. Bring your troubleshooting list with you, as well as a notepad to keep notes of the environmental concerns you have. Again if you are unable, have a friend or family member help you with this.
HEAL [Human Ecology Action League] board member Al Bouchard had a great deal of experience in observing environmental access criteria, such as the above, when he attended school as part of a vocational rehabilitation program. He suggests being aware of exhaust fans outside public buildings, such as dorms. These can cause access barriers, as they did for him when he needed to cross a walkway into another building without having severe breathing problems. Will you need to be in a room with computers? Check out what is or is not being done to shield users from EMFs [Electro-Magnetic Fields].

Al further suggests that you look for areas in buildings that, if buildings are cleaned with high-VOC cleaning solvents, will be safely sectioned off from the fumes. Check for overhead vents in ceilings to make sure they are not blowing fumes from other areas into these safe areas. Does a posted schedule tell when certain cleaning solutions have been used or pesticides sprayed? Do doors open easily for access with an oxygen tank? Do doors admit street pollutants into foyers?

There are many other environmental access considerations you may observe that are not mentioned here. Be sure to include them on your list.

WHAT TO DO WITH THAT CHECKLIST

Once you have your checklist, write a neat, one-page letter to the school principal, hospital administrator, corporate CEO, chain store owner, store manager, or whomever it may concern. Cite what you liked about their establishment on your last visit there, what they did right in the way of addressing environmental accessibility issues, and what you feel they could improve upon. Be sure to include a copy of your filled-in checklist with their company name as it appears in your letter. If the establishment did not meet any of your environmental accessibility criteria, politely tell them why, how they could improve, and your regret at not being able to access or patronize their institution or establishment in the meantime. Always have someone double check for grammar and punctuation, so your reader will not be distracted from your vital message.

Environmental access is not going to happen overnight but it will happen. A great many people have been addressing this issue for some time. Eventually, we will all have greater access to the places we need to go.

Melanie S. Lyle, disabled by MCS 15 years ago, is a writer and web developer attending Indiana University PUI through a web-based distance learning program. As a student in the computer program, she has obtained an Information Technology certification through IUPUI and is currently pursuing an advanced IT certification. She has written and published articles for HEAL nationally and locally, written, published, and performed her poetry at local events, and is in the process of developing e-commerce sites for 2 small businesses.
Chronic Neuroimmune Diseases
A Question of Access:
Sonoma County Public Library and Beyond

By Melissa Kaplan
September 25, 2000
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http://www.sonic.net/cnds/librarymcs.html
and Melissa Kaplan
“People with MCS have been ostracized by their families, friends, the community, and, too often, the medical profession, despite MCS and environmental illness (EI) having been documented in the medical literature as being a physiological – rather than psychosomatic – disorder as early as 1952. Because their reactions to exposures are often so extreme and seemingly bizarre - and not experienced by unaffected individuals - most people with MCS just quietly leave and say nothing rather than risk being further insulted and ostracized....”

--Melissa Kaplan
On Tuesday, September 12, I went to the Northwest branch of the Sonoma County Public Library, knowing that it was reopened again after being "refurbished". It didn't occur to me, until after I was inside and my skin and respiratory tract were assailed by the fumes from the new carpeting, that "refurbished" meant new carpeting. I didn't smell paint, just carpet. The room was very stuffy, as if the ventilation system wasn't on.

I asked the reference librarian if she could have someone put up a sign saying "new carpeting" so that others like me could decide whether they wanted to risk it or not. I left her my card with my web address on it, saying that I had a lot of information on MCS at my CND site. She said she would have to refer it to her manager who was in charge of signage. I was in there barely 10 minutes, and by the time I got home (I live about 2 miles away min away), my nose was clogged with blood clots and I ended up passed out for the next 9 hours or so, a typical response to various chemical fumes.

I went on Wednesday, 9/13, to drop a book off and saw no sign; I left it in the night deposit box, and left.

When I got home, I called the branch manager. She said that she didn't see any reason to put up a sign (no one else complained, and they did follow EPA recommendations), but she had referred it to her supervisor who had stopped in that day. I called and left a message for her supervisor, Virginia McClaren. She called me back on Thursday, late afternoon.

Basically, their position is: No. The stated and implied response was: No one else complained, including employees with asthma and allergies, so I really can't be that sick (and if I really am, how do I manage to go into doctors offices and things), and besides, no one reads signs anyway. I stressed the complexity of our reactions, how they were not like asthma or allergies, and that I didn't really want to have to escalate this into an access issue.

I heard nothing more until I received a note from one of the individuals I had emailed about this situation that when she called Virginia, Virginia told her that there was a sign up. I went by on Tuesday, 9/19, to drop off a book, and saw that there was, indeed a sign. While not referring to those with chemical sensitivities, it was a nice, cheery sign welcoming library patrons back to the re-opened library with its new carpet, ceiling tiles, and carrels. I decided that, despite the fact no one from the library called to say there was now a sign, that I would write a thank-you letter. As I got into it, however, I decided it really should be escalated into an issue. Herewith is my letter to the library.
September 21, 2000

Virginia McClaren
Sonoma County Public Library
3rd & E St
Santa Rosa, CA 95404

Dear Virginia,

Thank you for putting a sign up at the Northwest Branch of the library. I had the opportunity to see it the other day when I went to return some books - using the after-hours drop box, rather than going inside, as I am still suffering the lingering effects of my brief exposure to the library over a week ago.

I was going to make this a short thank-you letter, but as I went over my notes and discussions with other members of the community, the enormity of the lack of understanding has prompted me to do take this opportunity to clarify and discuss a few things.

1. Multiple chemical sensitivity (MCS) is neither asthma nor "allergies" as people typically understand them. Unlike these two conditions, there is no effective treatment. While asthma attacks and allergic reactions can be halted by inhaled or oral medications, MCS cannot be so easily mitigated: once the exposure has occurred, the reaction must run its course. While expensive intravenous drugs, steroids, and anti-seizure medication may help some individuals, these drugs are generally not at hand unless the person is rushed to the emergency room. For those who suffer "lesser" reactions, it may take hours, days, or weeks to recover from the exposure.

   In my case, I had a bloody nose by the time I got home (less than 15 minutes after walking into the library) and suffered a collapse from severe fatigue and weakness lasting almost 9 hours. I continued to experience hypersensitivity, nasal bleeding, impaired respiratory function, and extreme, debilitating fatigue for well over a week. For exposure to cats, I can take a pill. For new carpeting or paint, there is nothing like that that will get me back to functioning at my normal level in a relatively short period of time. Thus, the difference between asthma and common allergies is an important distinction to keep in mind when it comes to MCS.

2. People with MCS have been ostracized by their families, friends, the community, and, too often, the medical profession, despite MCS and environmental illness (EI) having been documented in the medical literature as being a physiological - rather than psychosomatic - disorder as early as 1952. Because their reactions to exposures are often so extreme and seemingly bizarre - and not experienced by unaffected individuals - most people with MCS just quietly leave and say nothing
rather than risk being further insulted and ostracized, exactly the feeling I got when talking to you and Beverly at the Northwest branch. Unlike most others with this disease, however, I tend to speak up.

3. Corporations and the media have long known that the letters and phone calls they get represent only a fraction of all those individuals who have the same or similar opinions of those who actually call or write. At one time, the ratio was estimated to be 1:500, with every single communication representing 500 people with the same or similar opinion. Just because you don't get a lot of complaints about a problem, from the public or your own employees, does not negate the fact that a problem exists.

In fact, since I spoke with you, I have heard from several people who had reactions or, knowing that there was new carpeting, skipped going to library all together. (The Northwest and Central branches may seem together to you and others who are healthy, but they are very far apart for those who are not well and for whom every minute spent in the car and in traffic adds an additional burden on already over-loaded immune systems). I have also heard from healthy individuals who got sick when they were in Northwest branch and some other county buildings shortly after they were painted and carpeted who did not at the time they were there attribute their physical reactions to the fumes. This is one of the reasons why MCS is creating a significant health burden and increasing absenteeism without being identified as such: most healthy people simply do not realize that the man-made environment is causing toxic reactions in them.

4. Your new carpeting may have met EPA guidelines, but those guidelines are for people who aren't already suffering from MCS; instead, they are an attempt to mitigate the impact of the renovation and, hopefully, reduce the number of future victims. Unfortunately, these guidelines often do not go far enough, or they are observed more in the breech than in fact. The EPA itself recommends that even low-emission carpeting be rolled out and aired for several days before installation, and that ventilation be done around the clock for several days before the site is occupied again.

The library may have had low-emission carpeting installed, but if the installers did not unroll and air it out for several days before the actual installation, and the building's ventilation system was turned off during hours workers were not there or has insufficient fresh air intake, the fumes will not dissipate adequately. That would account for the fact that I and those who have not spoken up were immediately overcome by the fumes and stuffiness in the branch, and other suffered a generalized feeling of "unwellness" after spending some time in there.

5. When I spoke to you, you asked about how I dealt with going to medical offices, your tone sounding as if fumes and fragrances couldn't really bother me as much as I said they did. To reiterate my response, besides my physicians who, being aware of the effects of chemicals and fragrances on their patients, I have ventured into very
few medical offices because of the fragrance/chemical problem. I did once have to go into the 1111 Mendocino medical building for x-rays. Between the recent chlorination of the two-story indoor waterfall and pool, the painting of an office suite on the floor the radiologist was on, and the perfume worn by the x-ray technician, I was reeling from a migraine-like headache which lasted 48 hours, wheezing, and ended up collapsed for a day by the time I left 25 minutes later.

The last time I saw my gynecologist, I lost my voice and got a ferocious headache within seconds of walking in the door because of a patient in the waiting room who was wearing perfume and hairspray. I gasped to the receptionist that I would wait in the courtyard. The doctor very nicely met me out there; needless to say, it was fortunate for all of us that, on that particular day, my visit did not include a pelvic exam.

6. Finally, the YWCA put up signs two weeks before they repainted and treated their pool with chemical notifying their members that this work was going to be done, and left the signs up afterwards as a caution for those who are chemically sensitive. They did not need to be urged or argued into doing so. Why is it that city, county, and medical facilities cannot do the same?

Despite the paltry library holdings, there is an increasing body of accessible literature on MCS and the physical - and societal - ramifications of the disease. Some of them available locally or though online resources include:

- **Multiple Chemical Sensitivity: Living with Environmental Illness**
  Stephen Edelson, with Jan Statman (615.902)

- **A Canary's Tale: The final battle: Politics, poison and pollution vs. the environment and public health**
  Jacob B. Berkson (615.9)

- “Is your office killing you?” - http://wwwsonic.net/cnds/sbsbusweek.html
  Michelle Conlin, Business Week, June 5, 2000, pp 114-128

- **Chemical Exposures: Low Levels and High Stakes**
  Claudia S. Miller, Nicholas Askounes Ashford (ISBN 0471292400)

- “Multiple Chemical Sensitivity (MCS): What it is, what it is not, and how it manifests.” - http://www.sonic.net/cnds/bastienmcs.html

- “Clinical and Immunological Responses in Subjects Sensitive to Solvents” - http://www.sonic.net/cnds/mcsmark.html
“The Indoor Air We Breathe: A public health problem of the 90's” –
http://www.sonic.net/cnds/airwebbreathe.html
L. Christine Oliver and Bruce W. Shackleton, Public Health Reports,
Sept-Oct 1998

I strongly suggest that whomever is in charge of facility management, public relations,
and human resources read these and related materials. Additional information on
accommodations for fragrance sensitivities and multiple chemical sensitivity can be
found at the University of West Virginia’s Job Accommodation Network (JAN) at
http://janweb.icdi.wvu.edu/.

In case you do not get around to reading it, I thought I would share this quote from the
Business Week article:

    Experts predict that the 5% to 10% of the population that is allergic to chemicals
will grow to 60% by 2020.

What this means is that in Sonoma County, based on the 1998 population figures and
its estimated annual increase, there are presently 22,935-45,870 people who suffer
from MCS. While I may have been the only one to voice the request for a sign, I am not
the only one whose access and health are affected by the lack of signage - and
understanding - that is prevalent in the public library system and in this county. The fact
that there are only two books in the entire system on this problem is indicative on how
little recognition it receives here.

Just in case my complaint still is difficult to understand, let me try to illustrate the
inappropriateness of the reaction I received to my request and statement of concerns:
Telling a person with MCS that there is only a little fragrance or very low emissions is
like telling someone in a wheel chair that "there are only a few steps." Any barrier that
prevents access - or precludes the ability to choose to access - is a barrier.

All I asked for was a temporary sign on one branch library door to alert those with MCS
that a potential barrier lay inside the Northwest branch. Perhaps the next time someone
asks they won't have to go up the food chain to get it done.

Melissa Kaplan

cc:  Paul L. Kelley, County Supervisor
      Mark Kostielney, Director, Sonoma County Health Services
      Roger Pearson, Library Director
      Marc Richardson, Assistant City Manager/ADA Coordinator
      Hon. Lynn Woolsey
"In providing program access city governments are not required to take any action that would result in a fundamental alteration to the nature of the service, program, or activity in question or that would result in undue financial and administrative burdens."

The ADA and City Governments: Common Problems
http://www.usdoj.gov/crt/ada/comprob.htm

A simple sign is hardly a "fundamental alteration" or "undue" burden.
Resources
Resources

Chemical Injury Information Network (CIIN)
Contact: Cynthia Wilson
P.O. Box 301
White Sulphur Springs, MT 59645
406-547-2255

CIIN is a nonprofit organization dedicated to education regarding the negative effects of chemicals on health and publishes the monthly newsletter *Our Toxic Times*.

Chemical Sensitivity Disorders Association (CSDA)
Contact: Larry Plumlee, M.D.
5717 Beech Avenue
Bethesda, MD 20817
301-897-9614

Publishes *The Chemical Sensitivity Connection* newsletter.

Ecological Health Organization and Action Coalition (ECHO)
Contact: Elaine Tomko
P.O. Box 0119
Hebron, CT 06248-1119
860-228-2693
http://members.aol.com/ECHOMCST/home.html

ECHO is a statewide nonprofit advocacy, support and referral organization for people with MCS and other interested parties. They publish a bimonthly newsletter.

Environmental Health Network (EHN)
P.O. Box 1155
Larkspur, CA 94977
415-541-5075
e-mail: wilworks@lanminds.com
http://users.lanminds.com/~wilworks/ehnindex.html

Publishes the bimonthly newsletter *The New Reactor*.

Health Coalition of Western MA
Contact: Peggy Wolff
P.O. Box 61114
Leverett, MA 01054

Statewide education, advocacy, and support organization.
Human Ecology Action League, Inc. (HEAL)
P.O. Box 29629
Atlanta, GA 30359-0629
404-248-1898
e-mail: HEALNatnl@aol.com
http://members.aol.com/HEALNatnl/index.html

This organization emphasizes support rather than advocacy. They publish *The Human Ecologist* quarterly.

**MCS: Health and Environment**
Contact: Lynn Lawson
P.O. Box 1732
Evanston, IL 60201
847-866-9630
e-mail: Lynnword@aol.com

Publishes the monthly newsletter *Canary News* and provides articles and resources and a lending library of books and tapes.

**MCS Referral & Resources**
Contact: Albert Donnay
508 Westgate Road
Baltimore, MD 21207-6631
410-362-6400

Provides professional outreach, patient support, and public advocacy as well as referral and research services for MCS professionals, patients, elected officials, and the media.

**National Center for Environmental Health Strategies (NCEHS)**
Contact: Mary Lamielle
1100 Rural Avenue
Voorhees, NJ 08043
856-429-5358
e-mail: ncehs@ncehn.org
http://www.ncehs.org

Provides education, research, support, and advocacy services on environmental and public health issues.

**National Coalition for the Chemically Injured (NCCI)**
Contact: Alice Osherman or Larry Plumlee, M.D.
2400 Virginia Avenue NW
Suite C-501
Washington, DC 20037
847-776-7792 (Alice/summer); 941-756-1606 (Alice/winter); or 301-897-9614
Coalition of MCS support and advocacy groups in the United States.

**Ohio Network for the Chemically Injured**  
Contact: Toni Temple  
6179 Stratford  
Parma Hts., OH 44130

Regional activist, education and support group.

**Share Care & Prayer**  
Contact: Janet Dauble  
P.O. Box 2080  
Frazier Park, CA 93225

A Christian organization that provides support through prayer, provision of uncontaminated clothing, and other services.

**The American Academy of Environmental Medicine (AAEM)**  
8345 Walnut hill Lane  
Suite 200  
Dallas, TX 75231  
214-368-4132  
e-mail: inform@ehcd.com  
http://www.ehcd.com

A professional organization of practitioners of environmental medicine.

**The Jeremiah Project**  
Contact: Rev. Linda Reinhardt  
HC 1 222 Soft Wind  
Canyon Lake TX 78133  
830-935-4618  
e-mail: jeremiah@texannet.net

Offers an interdenominational ministry with and for people who are chemically sensitive and/or chemically injured. Publishes bimonthly newsletter *I Am Jeremiah.*