EMERGENCY MEDICAL SERVICES

FIRST...DO NO HARM:
The Challenge of Patients with Multiple Chemical Sensitivities (MCS)

By: Ann McCampbell, M.D.
Santa Fe, New Mexico

Prior to 1988, I was a healthy, athletic physician who played drums in a rock band. A year later, I was severely disabled with what is known as Multiple Chemical Sensitivities (MCS). The onset was subtle, with slowly worsening food intolerances, progressing to the point I could only eat three green vegetables. By then I was also having severe reactions to inhaled substances and had developed headaches, fatigue, heart palpitations, abdominal pains, nausea and severe diarrhea. Like so many others with MCS, I could no longer tolerate where I lived and was forced to live outside in my yard, the car, or a makeshift shelter.

Despite some improvements since the late 1980's, I still face food intolerances, malnutrition, and adverse reactions to a wide array of chemicals commonly found in the air, foods, and water of our everyday environment. I go to few places outside my home in order to avoid exposures to cigarette smoke, pesticides, perfume, vehicle exhaust, cleaning products, and other toxic fumes which make me sicker. I still do not know what caused my MCS although I do know that I am sick now and that my illness is real and has been devastating.

What is MCS?

Persons who have Multiple Chemical Sensitivities (MCS) experience adverse health reactions from chronic exposure to a wide spectrum of certain chemicals at levels which ordinarily do not affect others. The stimulating agents are found everywhere in our modern world: pesticides, new building materials, new carpets and furniture, glue and solvents, paint, perfume, many personal care products (detergents, fabric softeners, shampoos, hairsprays, mousse, soaps, lotions, deodorants), tar and asphalt fumes, smoke, cleaning products, disinfectants, vehicular and industrial exhaust fumes, fresh ink, new plastics, and synthetic clothing. Symptoms can be provoked by even minute amounts of substances being inhaled, ingested, or absorbed through the skin. Many with MCS also react to mold, dust, pollen and animals, and there are significant overlaps between MCS and the syndromes of Chronic Fatigue Immune Dysfunction Syndrome and Fibromyalgia, a painful chronic condition of joint and muscle pain.

MCS occurs in people of all ages, races, and socio-economic conditions. Women are affected more frequently than men. Although the exact prevalence of this disorder has not yet been clearly defined, a 1995 randomized study in California found that 16% of the population reported some degree of chemical sensitivities and 7% said they had been diagnosed with MCS. Three physicians in northern New Mexico who treat patients with MCS estimate that collectively they have diagnosed 1500 new patients in our area over the past two years.

The severity of this illness varies greatly, from those with only mild symptoms like skin rashes from wearing latex gloves to a severe and disabling chronic illness which forces people to alter every aspect of their lives. People with MCS often lose their jobs, homes, careers, family and friends because their lives change so drastically. They are unable to go into most buildings and some become imprisoned in their homes where they can establish a safe environment free of the chemicals that cause their worst reactions. The isolation imposed by these chemical barriers and the lack of understanding about MCS contribute significantly to the devastating nature of the illness.

Although the medical community has generally been slow to understand or accept MCS as a "real" illness, there are some physicians who understand and treat the condition. It has also been recognized as a potentially disabling condition by the federal Social Security Administration, Department of Housing and Development (HUD), Environmental Protection Agency (EPA), and the National Academy of Sciences. The newly-built medical facility in Taos - Holy Cross Hospital - was constructed with rooms designed to accommodate chemically sensitive patients by not only utilizing less-toxic building materials but also establishing guidelines for staff to refrain from wearing perfumes, personal care products and utilizing less-toxic cleaning methods.

Causes of MCS

MCS is thought to result from exposures to toxic chemicals, although the exact etiology of MCS is unproven and the mechanism of the illness is unknown. Some develop MCS after a single major exposure while others seem to develop symptoms slowly following cumulative events. Many of those with MCS report the onset of their illness after moving into a new home or working in recently remodeled offices. Many members of the health care profession have developed this disorder, seemingly after chronic exposure to disinfectants and other chemicals found in hospital and other health care settings.

The Symptoms of MCS

The symptoms of MCS vary greatly and are unique to each person, but the unifying factor is that chemically sensitive people experience the onset and/or exacerbation of their symptoms following exposure to chemicals. The diversity of symptoms and the lack of a clear causative agent has contributed to the bewilderment of medical professionals who, at times, throw up their hands in frustration and attribute the symptoms to a pure psychiatric problem.

The symptoms of MCS run the gamut of all the body systems: headache, fatigue, sleep disturbances, dizziness, heart palpitations, respiratory difficulties, swollen lymph nodes, abnormal taste sensations, impaired circulation, gastrointestinal problems, joint and muscle pain, weakness, loss of coordina-

(Continued on page 3)

New Mexico Department of Health,
Community Health Systems Division, Emergency Medical Services Bureau
Volume 15, Number 3-October, 1996

(Continued from page 4)

tion, nerve irritations, and even seizures. Many cognitive symptoms can also surface such as clouded thinking, difficulty in concentration and communicating, memory loss, and hallucinations. Emotional symptoms may occur as well, such as depression, panic attacks, and emotional outbursts. Finally, persons with MCS may have typical symptoms associated with allergies such as itchy eyes, nasal congestion, sinusitis, asthma, hives and other rashes, and even anaphylactic reactions.

The onset and severity of symptoms following an exposure varies from person to person based on their general state of health, recent cumulative exposures, and other unknown factors. Symptom onset may be delayed by hours or even days from exposure. The duration of an individual's reaction can also vary from seconds to a few weeks or months.

Diagnosis and Treatment of MCS

The diagnosis of MCS is often easy to make but difficult to prove, since there are no agreed upon diagnostic criteria for this disorder. Like other conditions with limited physical and laboratory findings - e.g. headaches - the physician must often rely primarily on reports of the patient's array of symptoms resulting from environmental exposures. Various tests such as brain scans, immunological studies, enzyme functioning, and neuropsychological tests have shown abnormalities in many people with MCS, pointing to possible damage to the immunological and central nervous systems.

There is no known cure for MCS, but a variety of treatments can help reduce the reactions and improve the overall health of people with the disorder. Avoiding exposure to stimulating chemicals is of prime importance, but not always possible in the environment of modern society. Treatment to self-administer those agents include nutritional supplements, detoxification techniques, allergy desensitization and correction of hormonal imbalances. Complementary medical techniques such as acupuncture and homeopathic medicines have also been found to be effective.

Although some people seem to fully recover from MCS, most unfortunately demonstrate a chronic relapsing course characterized by spurts of improvement countered with distressing setbacks. MCS is rarely fatal in itself, but deaths have been known to occur as a result of severe bronchospasm, heart irregularities, and malnutrition. Tragically, suicide is also a factor of morbidity for those with MCS who find their worlds overwhelmingly intolerable due to the pain, isolation, and hopelessness associated with this illness.

MCS and EMS

What does all this have to do with EMS? Like all people, those with MCS occasionally find the need to access emergency care, perhaps at even a greater rate than others because of their precarious health. But many with MCS have a deep fear of seeking such help. Probably the biggest reason for not calling for help is the fear of having a serious, even life-threatening, reaction to an administered drug. They also do not want to worsen their condition by being exposed to ambulance exhaust (especially diesel), perfume, cologne, scented laundry products and cigarette smoke residue emanating from the EMTs, and various emergency equipment such as plastic oxygen masks, intravenous fluids in plastic bags and latex gloves. Those with MCS also worry about being transported to a hospital against their will.

Another element of concern has more to do with the sometimes insensitive approach of health care providers when faced with a MCS patient. Although many EMTs have been reported to be kind, courteous and respectful of MCS patients, others have been rude and ready to assume the person they are treating is "crazy." These fears within the MCS community has unfortunately led patients to prolong calling for help through 911 until their condition has deteriorated drastically.

In Knowing how to provide emergency treatment to a chemically sensitive person who is in active distress is admittedly difficult and presents a great challenge to the EMT. The most important thing for an EMT to do is to listen to the patient, accept what they are saying, and respect their limits. This, of course, has to be balanced with providing life-saving measures as taught in EMT training and authorized through treatment protocols. Bear in mind, too, that MCS patients may have difficulty communicating verbally if they have been, or continue to be, chemically exposed.

(Continued from page 5)

gual antigens or homeopathic medicines, contact medical control for advice and concurrence to allow the patient to self-administer those agents.

- **Intravenous fluids in plastic bags may be harmful –** ideally, those with MCS should receive i.v. solutions from glass bottles, but since these are not standard on ambulance vehicles because of safety concerns, consider that an i.v. may not be best for the patient unless critically life-threatening conditions exist. Also, avoid glucose solutions if possible and use isotonic solutions.
- **Avoid the use of drugs if possible –** if there needs to be a balance between what is life-saving and what may potentially harm a patient, MCS sufferers are often sensitive to many drugs and preservatives. Listen to the patient's concerns, history of reactions to medicines, and contact medical control for advice on administration of any medicine.
- **Avoid use of latex gloves whenever possible –** it is understood that universal precautions are of great importance to EMT care, but if alternatives to latex gloves are available, these should be used.

There are scores of other suggestions that may improve the EMS environment in treating MCS patients, such as cautious use of disinfectants in the vehicle, hypoallergenic tapes and dressings, and the cleaning practices for linens and towels. Details on these factors can be obtained by contacting Barak Wolff at the EMS Bureau.

It is unfortunate that most MCS patients do not wear identification bracelets that would notify the EMT of their condition, but many MCS patients are unable to wear metal bracelets due to allergies and sensitivities. Hopefully, a standardized method of identification can be developed in the future that will be helpful for emergency providers and patients alike.

In summary, MCS is a serious and complex illness that is poorly understood by most health care providers. People with MCS may have to access emergency services because of an exacerbation of their MCS symptoms or from an unexpected accident. In either case, it is important for EMT's to be familiar with MCS so that care can be balanced between what is life-saving and appropriate versus what can actually produce more harm to the patient. Listening to the patient, keeping an open mind, and being flexible within guidelines goes a long way in achieving the best outcome possible for all involved. Utilizing direct medical control when conflicts arise between standard emergency procedures and the wishes of an MCS patient are of utmost importance.

As more is discovered in the future about this complicated disease, EMS will undoubtedly adjust its protocols to provide better procedures and treatments for MCS patients, while continuing to strive to " do no harm."

The Stories of MCS

Those who have MCS often face complex challenges that the populace at large will never experience. In the stories of chemically sensitive people in my community, their tales begin to show the faces of real people.

When K.T. developed MCS, neither she nor her doctor understood what was going on. She experienced a frightening series of events when she was admitted to a hospital to readjust the level of medications she was taking to deal with the anxiety and insomnia associated with her MCS. The hospital environment, especially the perfume and cigarette smoke, produced more severe reactions and an evaluation by a staff psychiatrist interpreted her behavior of trying to avoid them as "anti-social tendencies". Against her wishes, she was transferred to a county psychiatric facility, but by the time she arrived there, her thinking had cleared so completely that she was considered not appropriate for admission. However, certain items developed with the legal processing of her discharge and she was forcibly detained for three days until her brother could manage her release. She describes this experience as "a total nightmare".

While rollerskating, S.S. accidentally fell and fractured her wrist. She told the responding EMTs about her severe MCS and instructed them not to give her any medicines, but she was not reassured that they would comply. In the hospital's ER she attempted to communicate the same history to the doctor but was treated as if she was paranoid or hysterical. In addition, the emergency doctor refused to call her private physician (who was familiar with her chemical sensitivities) to get advice on how to treat her.

When R.T. accidentally ingested concentrated hydrogen peroxide, a call to the Poison Control Center initiated a 911 response. When the medics arrived, R.T. was vomiting repeatedly and unable to clearly describe her history and her fear of reactions if she was exposed to harmful chemicals in the ambulance and hospital. Luckily, a neighbor, who was also chemically sensitive, was available and advocated for R.T., including advice for the EMTs not use the plastic oxygen mask and try to limit AT's exposure to vehicle exhaust and their cologne. She had a less harmful transport to the hospital after this information was shared and accepted.

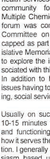
A 43 year old woman, J.C, became ill after working in an office that was undergoing major remodeling. The installation of a new carpet produced extreme fatigue, dizziness, trouble thinking, and difficulty in speaking. Since then, she has been disabled and unable to work. She now needs to use air filters in her home and car, and frequently must wear an industrial respirator when she goes out. If she catches a whiff of perfume, she feels like someone hit me across the head with a baseball bat."

A 44 year old man, C.L., has been forced to move numerous times in the past three years in an effort to find living accommodations that are free of formaldehyde-containing building material. This agent is commonly found in particle board, plywood, and carpeting. Exposure to formaldehyde produces foggy thinking and memory loss. Even in C.L. that he is unable to balance a checkbook or read a book. He also suffers from fatigue, depression and severe digestive problems. The physicians he has gone to for care have not helped with either a diagnosis or effective treatment of his illness.

In summary, MCS is a serious and complex illness that is poorly understood by most health care providers.

FOCUS on
EMERGENCY MEDICAL SERVICES
"A System to Serve People"

New Mexico Department of Health,
Community Health Systems Division, Emergency Medical Services Bureau
Volume 15, Number 3-October, 1996



FROM THE CHIEF - *Barak Wolff, M.P.H.*

"Scared to Death" of Having to Call 911

Several months ago I was invited to be on a health services panel as part of a full day community forum regarding people with Multiple Chemical Sensitivity (MCS). The forum was convened by the Governor's Committee on Concerns for the Handicapped as part of their response to a Legislative Memorial passed in the last session to explore the incidence and problems associated with this difficult medical condition. In addition to health, the forum explored issues having to do with employment, housing, social services, etc.

Usually on such panels, I expect to take 10-15 minutes to explain the components and functioning of the EMS system and how it serves the needs of the entire population. I generally speak with pride and enthusiasm based upon my positive sense of EMS in New Mexico. On this day, however, I never got the opportunity. After very brief introductions, the next hour was spent listening to testimony from the impacted public. Each person could speak for no more than 3 minutes so we ended up listening to 15-20 people, some via speaker telephone from their homes and offices.

Although the testimony varied, in most cases it was very personal and very powerful. These were people who are either afflicted with MCS, sometimes referred to as Environmental Illness (EI), and/or caregivers who work with these patients/clients as physicians, nurses, social service workers, family members or advocates. They had a lot to say about the incredible problems and hardships endured in accessing health care, obtaining appropriate health services, getting insurance companies to reimburse for their treatments, etc.

At first I listened with interest, but the issues raised had nothing to do with EMS. Then several folks in a row shared experiences in having to call 911 and encountering EMTs who smelled of cologne or cigarette smoke or who were not responsive to their concerns about vehicle exhaust fumes, the plastic in the oxygen mask, etc. They spoke of actually being afraid of having to call EMS and risk being taken to a hospital where they might be assaulted by toxic chemical fumes and sometimes unwanted treatments that might actually worsen their condition.

The vehemence of their concern caught me by surprise. All I could think to say to be helpful was that they always have the right to refuse care or transport. One woman said that my comment "was good in theory", but when she was scared, in pain and perhaps disoriented, she found it impossible to rationally counteract the decisive nature of the EMT's desire to put her in the ambulance and follow their protocols. Some of these people were indeed "scared to death" of being in a situation where 911 had to be called.

As a result of this disturbing feedback I committed to working with the advocates for MCS and related conditions to provide some educational materials and work through some approaches to dealing with these and other patients who have conditions that pose special problems for emergency responders. Over the last several months, State EMS Medical Director, Tim Fleming, EMS Region I Training Coordinator, Fred Shumate and I have met with Dr. Ann McCampbell on several occasions, have read various articles and materials and have put together a file on MCS. We even asked Santa Fe Fire Department to bring over a fully stocked ambulance so that Dr. McCampbell and several MCS sufferers could go through it and suggest various materials and products that we use routinely in EMS.

As a result of this exchange, we worked with Dr. McCampbell, a general practitioner in Santa Fe, to accomplish the article on page 4-6 entitled "First Do No Harm: the Challenge of Patients with MCS". I sincerely hope that you read the article with care and understanding and apply the lessons and recommendations in your EMS practice, for these, and all other, patients. If you want more information on MCS or wish to discuss this further, please give me a call at 827-1400.