

Transcript for Multiple Chemical Sensitivity: A Short Introduction

(Note that the video was slightly revised in August 2016)

First screen says the following:

This short introduction to multiple chemical sensitivity contains excerpts from various documentaries made by Alison Johnson and Richard Startzman. Many of these can be viewed on the website www.alisonjohnsonmcs.com.

Alison Johnson
Author/Producer/Director
www.alisonjohnsonmcs.com

Alison Johnson: Hello. I'm Alison Johnson. For over a decade I have been writing books and making documentaries on the subject of multiple chemical sensitivity. In the fourteen years that have passed since I produced and directed my first documentary, *Multiple Chemical Sensitivity: How Chemical Exposures May Be Affecting Your Health*, more and more people have succumbed to this condition. Hardly a day goes by that I do not hear from someone who is close to despair as they see their former life slipping away from them as they struggle with a condition that has been largely ignored by the medical profession.

For decades there was great resistance to the idea that smoking could be a health hazard. Today there is a similar resistance to the concept that exposure to the ever increasing number of toxic chemicals in our daily lives could cause health problems.

A few years ago a taxicab driver from Las Vegas e-mailed me to say: "I was making good money driving a taxi but had to resign because the other driver would spray it with air freshener. Eventually the cab made me so sick I had to quit." In fact the city of New York has banned the use of air fresheners in all its city cabs. This taxicab driver from Las Vegas is just one of millions of Americans who are trying desperately to hold on to jobs that are damaging their health and making them sicker with each day that passes.

At this point, the following list of important MCS symptoms scroll slowly across the screen:

Common MCS Symptoms

- Headaches
- Migraines
- Extreme fatigue

Muscle pains
Joint pains
Difficulty concentrating
Insomnia
Irregular heart beat
Asthma
Sinus problems
Depression
Eczema
Rashes
Memory problems
Anxiety
Bloating
Nausea
Vomiting
Intestinal problems
Seizures

Next two screens appear containing the words below:

Narrator: People with MCS can have a wide variety of symptoms as the result of chemical exposures, including headaches, asthma and other breathing problems, joint or muscle pains, extreme fatigue, gastrointestinal problems, and severe memory loss. One confusing aspect of multiple chemical sensitivity is that different patients having different symptoms. A given patient, however, will usually have the same symptom in response to a given exposure, perhaps getting a headache after exposure to paint or getting arthritic pains after exposure to natural gas.

Alison Johnson: People who develop MCS begin to react to chemicals that never bothered them before, chemicals that they encounter in everyday life in substances such as paint, perfume, pesticide, cleaning products, gasoline, diesel exhaust, cigarette smoke, new carpets, building materials, and air fresheners.

Narrator: L. Christine Oliver, an Associate Professor at Harvard Medical School, is the former director of Occupational and Environmental Medicine at the Massachusetts General Hospital.

L. Christine Oliver, M.D., M.P.H., M.S.
Harvard Medical School
Associate Professor of Clinical Medicine

Christine Oliver, M.D.: Multiple chemical sensitivity, or MCS, is a multisystem disease that is characterized by symptoms associated with the exposure to low levels of chemical vapors. These levels of exposure are commonly found in the ambient environment. Systems that are affected by MCS include the respiratory system, the neurologic system, the gastrointestinal system, the skin in some cases. For those with less severe illness and disease, symptoms may include cough, shortness of breath, headache in association with the exposure to chemicals on an elevator, or when they open a magazine and have a scented insert in the magazine. For those who are more severely affected, however, symptoms can

be truly disabling. They interfere with a person's ability to engage in gainful employment. They interfere with a person's ability to use public transportation. They interfere with a person's ability to live in a multifamily housing unit. They interfere with family life. They are isolating in short, so that individuals with MCS who are severely affected often feel very isolated. I see this in patients that I see at MGH. One reason for their isolation is that physicians do not get this disease, they don't understand this disease. Medical students are not taught about multiple chemical sensitivity. Physicians in training know very little about multiple chemical sensitivity, or MCS.

Alison Johnson: Some MCS patients have relatively mild cases. I myself was fortunate to be able to reduce the chemical exposures in my life sufficiently that I could return to normal activities. For many people with MCS, however, the condition can be quite debilitating, even life-threatening in some cases. Unfortunately, MCS can make it almost impossible for people to maintain their social life, to keep working, or even to find a safe place to live.

Bennie Howard: Hello everybody. My name is Bennie Howard. I'm the Acting Director of the Office of Disability Policy at the U.S. Department of Housing and Urban Development in Washington, D.C. Federal laws, specifically the Fair Housing Act, Section 504 of the Rehabilitation Act, and the Americans with Disabilities Act, prohibit discrimination on the basis of disability. HUD considers multiple chemical sensitivity to be a disability under these laws.

Alison Johnson: Four cataclysmic events have rocked the United States in the last two decades: the 1989 *Exxon Valdez* oil spill, the 1991 Gulf War, the destruction of the World Trade Center in 2001, and Hurricane Katrina in 2005. At first glance, these events might seem to have little in common, but all have left in their wake large numbers of people who are now chronically ill after exposure to large amounts of toxic chemicals. In my 2008 book *Amputated Lives: Coping with Chemical Sensitivity* I write about the devastating effects of these major toxic exposures.

A screen then appears saying:

Some of the following footage comes
from the Johnson/Startzman films titled:

Gulf War Syndrome: Aftermath of a Toxic Battlefield

The Toxic Clouds of 9/11: A Looming Health Disaster

A second screen next appears that contains the cover images of the above DVDs.

Roy Twymon: Since I've been back from the Gulf War, you know, I also notice that a lot of things bother me that never bothered me before. Different perfume, different cologne, gas, different smell of even smoke or cigarettes, you know, I just automatically get sick, and sometimes it takes me days or weeks to recover. One day I was on the elevator and someone got on there with some loud perfume, and then all of a sudden it hit me, and I got lightheaded.

Narrator: Roy's blood pressure shot up so high that the emergency room staff thought he was having a heart attack. He ended up spending four days in the hospital.

Tim Smith: You know, the chemical sensitivity is just becoming unreal, and you notice it now. It's before

when you used to pump gas, you'd just stand there and smell the fumes. Great, you know, this stuff don't bother me. And now you've got to try to hide and pump at the same time.

Lt. Gen. Ronald R. Blanck
Fmr. U.S. Army Surgeon General
Fmr. Cmdr. Walter Reed Medical Center

Dr. Ronald Blanck: In the mid-1990s, I commanded Walter Reed Army Medical Center. I continued to work on looking for causes for the illnesses suffered by many Gulf War veterans, illnesses that clearly were more than stress related. I looked at vaccines, I looked at exposure to smokes, to other toxic chemicals, petrochemicals, and so forth, all that were part of that battlefield experience, and I came to the conclusion that at least one of the explanations was multiple chemical sensitivity, something where a variety of toxic elements even at low levels by themselves in combination may in susceptible individuals be causing these illnesses, and I believe so much more work needs to be done on that, but it is clearly one of the explanations.

John Sferazo: So being an ironworker and being a person in the construction field, where every day you face some type of hazard, some type of danger. Well, right after we witnessed that collapse, we knew that we wanted to go into the Trade Center site. Meanwhile everybody else is running from it, and here you've got a bunch of guys, your first responders, that are looking to go in.

Bonnie Giebfried: We were one of the first units into the South Tower. The last thing I remember seeing actually was a helicopter trying to go to one of the towers to get people off the tower, hearing someone say it was going to blow and a humongous fire ball; it looked like a meteor coming at us.

John Sferazo: Since 9/11, the smell of gasoline and diesel fuel is such that I don't get out and even fuel my own vehicles. I don't even want it on my hands because of the odor. Being around the job sites and being around the smell of the diesel and the gasoline, I am so symptomatic to that involvement that I was constantly getting problems with my throat, I would wind up going hoarse, and I would lose my voice sometimes. The next thing you know from a sore throat, I'd have a chest infection, I'd get lung infections, then I'd get pneumonia, and this never ever happened to me before in my life. Now the smell of smoke actually ensickens me, sometimes giving me headaches. I know I can't use any type of cologne or aftershave. I can't take that smell, it's sort of like a burning inside my nostrils. I'm very acute.

Bonnie Giebfried: I can't be in restaurants because God forbid someone has perfume on. I can go into a fit. I can feel nauseous and throw up. My throat can close up. The multiple chemical sensitivity issues that have come from 9/11 have not been addressed. Household cleaners, Oh, my God, you just might just as well pack me up at that point and just send me to the hospital.

Joel Kupferman
New York Environmental
Law and Justice Center

Joel Kupferman: I've been tracking the firefighters post-9/11, and what many, many have told me and their medical reports have showed that they become hypersensitive to other chemicals that are out there. They could be fine for a while, they have, you know, respiratory problems. They're on 3/4 time, meaning that they're not on active duty, and boom, they'll come across perfume or other chemicals out there, even household cleaning chemicals, and they'll just become immobilized, and some of them just become so sick that they can't, they basically can't function on a daily level.

Christine Oliver, M.D.: There are those who believe that MCS is psychogenic, that is, that it is all in the mind. Based upon my experience over the past more than twenty years taking care of patients with MCS at the Massachusetts General Hospital, I have no doubt that MCS is a physical and a physiologic disease. It is not a psychogenic disease. There are often visible manifestations of disease in patients who come into my office. These include, for example, flushing of the face, swollen mucous membranes of the nose that are directly associated with exposures, in some cases increased heart rate, in some cases increased blood pressure. When these individuals are not exposed to chemicals, their skin is normal, their blood pressure is normal, and their heart rate is normal. Unfortunately, there is no laboratory test that has an MCS sign on it. You can't take a chest x-ray and diagnose MCS. You can't draw a complete blood count and diagnose MCS, and that's one of the difficulties. Hopefully, with research and improved understanding one day we will be able to do that, but presently it is not possible.

Alison Johnson: Many people with MCS are so sensitive to fragrances that they virtually become prisoners in their own home, unable to attend church, work, classes, or social gatherings because of the perfume, aftershave, shampoos, detergents, and fabric softeners used by others. To make matters worse, some of those who insist that MCS is just a psychologically based illness state that these people are suffering from agoraphobia, or fear of crowds. That's as cruel as saying to a paraplegic in a wheelchair, "Too bad you don't like to walk."

**Stephen Levin, M.D., Director, Mount Sinai
Occupational & Environmental Clinic**

Stephen Levin, M.D.: Another striking thing is that many of our patients are much more reactive to strong odors than they were before, not always with exactly the same reaction that they'll experience when they are exposed to cigarette smoke or bus exhaust, but they notice these odors more and find themselves reacting physically unpleasantly to these odors in ways they never did before. I have patients who cannot walk into a department store cosmetic area without experiencing shortness of breath and chest tightness in ways they never did before. I have patients who cannot get on an elevator where someone is wearing strong perfume or cologne without experiencing fairly intense respiratory reactions. We don't always understand why this is so, but it is extremely commonly reported among our World Trade Center responders and many of our patients say that they are simply unable to wear fragrances themselves or be around others—family members, friends—who wear such fragrances because they simply can't tolerate them

Christine Oliver, M.D.: The onset of MCS is often in association with a relatively high level of chemical exposure. It can occur, however, with lower level chemical exposures. I've seen a number of patients whose disease began during the course of their work in a building or an office with inadequate ventilation, with poor indoor air quality.

Alison Johnson: Before she developed MCS at age 32, Jenn Duncan had a lot going for her in life. She had excellent and creative jobs, she enjoyed dance, yoga, and African drums. I have spoken with many chemically sensitive people during the last three decades, but Jenn is definitely the worst case of MCS that I have encountered. She stands as an extreme example of the neurological effects that chemical exposure can induce in certain individuals.

While Alison Johnson is talking, a sentence appears at the bottom of the screen saying:

Jenn Duncan holds a B.S. from MIT & a master's degree from New York University.

Jenn Duncan: I had developed chemical sensitivity prior to 9/11. The office building where I worked

was doing renovations and after a prolonged exposure over several weeks in a poorly ventilated area to a number of those chemicals I had a number of strange symptoms and unusual things that were going on that then later on I realized developed into multiple chemical sensitivity and other chemical injury symptoms. After 9/11, with all the exposure of the smoke and the fumes blowing over from Manhattan into Brooklyn, I definitely experienced exacerbations and got even more debilitated. And, you know, being exposed just to cologne, or if I was out around traffic, or somebody smoking a cigarette, then it would make me disintegrate and have the disorientation, and the trouble breathing and the great pain, joint pain.

Spelling is hard; numbers are hard. I have dyslexia sometimes now. I always check and double check. I would write an envelope, and it would be returned because I mixed up my numbers. I never had a problem with numbers before. I did calculus and differential equations. If somebody asks me numbers or to spell something, it's really hard. Sometimes it helps me, I used a little sign language before, so I usually spell out just to help me get something physical to help me get the numbers or letters out. Sorry, I'm getting fatigued, so I'm trying to just ride the waves and hold my energy together.

Alison Johnson: Believe it or not, that was Jenn on one of her good days. We had also filmed her the day after a doctor's appointment. Jenn told us that exposure to several air fresheners and diesel fumes in the private medical transport that had taken her to this appointment had caused this temporary but sharp decline in her condition.

Christine Oliver, M.D.: In June of 2009, the CDC put on its internal website an indoor air environmental quality policy intended to maintain good indoor air quality in buildings in which its employees work. Among other things, the CDC policy states:

Scented or fragranced products are prohibited at all times in all interior space owned, rented, or leased by the CDC. This includes the use of the following products:

- Incense, candles, or reed diffusers
- Fragrance-emitting devices of any kind
- Wall-mounted devices, similar to fragrance-emitting devices, that operate automatically or by pushing a button to dispense deodorizers or disinfectants
- Potpourri
- Plug-in or spray air fresheners
- Urinal or toilet blocks
- Other fragranced deodorizer or reodorizer products

In addition, the CDC encourages employees to be as fragrance-free as possible when they arrive in the workplace. Fragrance is not appropriate for a professional work environment, and the use of some products with fragrance may be detrimental to the health of workers with the following: chemical sensitivities, allergies, asthma, and chronic headaches and migraines.

Alison Johnson: It is important to note that the EPA website lists air fresheners as a source of indoor air pollution.

At this point a screen appears showing the home page of Professor Anne Steinemann's website, and then a screen gives the web address for that website.

Narrator: Professor Anne Steinemann, a civil engineer who has taught at both Georgia Tech and the University of Washington, has analyzed the secret ingredients in several leading fragranced products like air fresheners and laundry products. Dr. Steinemann found significant numbers of toxic chemicals in these products. Dr. Steinemann's website, www.drsteinemann.com, contains extensive information about her studies.

Christine Oliver, M.D.: The CDC Indoor Air Quality policy is a very important policy and provides an example of what we should be doing in every workplace in this country. I think all workplaces should be fragrance-free. The number of people who are chemically sensitive and/or with diagnosed MCS is increasing on a daily basis.

Alison Johnson: In the last couple of decades, I have seen a rapid acceleration in the number of people reporting that they have developed chemical sensitivity. In 2009 Professors Stanley Caress and Anne Steinemann published in *The Journal of Environmental Health* the results of their national prevalence study of chemical sensitivity. In this national prevalence survey, 3.2 percent of the respondents said that they had been medically diagnosed with MCS. This result suggests that over ten million Americans are suffering from multiple chemical sensitivity. That's a number greater than the population of the state of Michigan. Journalists often refer to MCS as a rare condition. That's hardly the case.

Christine Oliver, M.D.: A fragrance-free policy allows these individuals who are chemically sensitive to continue their employment. As a result, they do not have to turn to Social Security Disability for income. Those who are not the beneficiaries of a fragrance-free policy are often unable to work and do find themselves on Social Security Disability.

Alison Johnson: It makes sense for employers to follow the CDC lead and establish fragrance-free workplaces so that as many people as possible who suffer from multiple chemical sensitivity can remain productive members of the workforce. Otherwise they are faced with the choice between living on the streets or trying to obtain Social Security Disability Income or Supplemental Income, which is barely enough to live upon. Keeping people in the workplace so they don't have to obtain public assistance to stay alive is a good policy for everyone, and it's particularly important as our country struggles to keep government costs under control.

Alison Johnson: In closing, I have a special request for those of you who are fortunate enough not to have developed multiple chemical sensitivity. Your efforts to treat those with MCS with kindness and compassion instead of skepticism will do much to make their difficult lives more tolerable.

Produced and Directed by Alison Johnson

Cinematography & Post-Production
by Richard Startzman

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Johnson/Startzman DVDs:

Multiple Chemical Sensitivity:
How Chemical Exposures
May Be Affecting Your Health

Gulf War Syndrome:
Aftermath of a Toxic Battlefield

The Toxic Clouds of 9/11:
A Looming Health Disaster

Alison Johnson's books:

Casualties of Progress:
Personal Histories from the
Chemically Sensitive

Gulf War Syndrome:
Legacy of a Perfect War

Amputated Lives:
Coping with Chemical Sensitivity

To order these books and DVDs, see:

www.alisonjohnsonmcs.com

To read the entire CDC policy titled
"Indoor Environmental Quality," visit:

www.chemicalsensitivityfoundation.org

A bibliography of articles on
chemical sensitivity published in
peer-reviewed journals also
appears on the above website.

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