

Multiple Chemical Sensitivity

Part 1: Medical information



People with chemical sensitivities are affected by chemicals at levels well below what bother healthy people. This article provides a comprehensive overview of the illness, the treatments and the impact on people's lives.

Keywords: allergic chemicals, allergic perfume, chemical sensitivity, MCS, multiple chemical sensitivity, environmental illness, symptoms, treatment, diagnosis, science

This article is based on scientific studies as much as possible. The disease is controversial and much is not yet understood about it, which has resulted in many myths.

We include nearly three hundred references to articles from scientific journals and other quality sources, which can provide more detailed information. They can also be helpful when discussing particular issues with health providers, or make it all more plausible when talking to people who are skeptical MCS is "real."

This author is a patient with thirty years of experience with all aspects of MCS. This is for informational purposes only and not intended to provide advice on diagnosis, treatment or other aspects. If you think you may have MCS, please consult a physician with experience in this illness.

This article provides much detailed information, which may be more than some readers are interested in. For lighter reading on MCS, go to www.eiwellspring.org/intromenu.html.

In part 2 of this article, we discuss what life is like with MCS and the reasons why it is so controversial. It is available at www.eiwellspring.org/health/IntroductionToMCSpart2.htm.

The many names of MCS

In the 1990s there were more than two dozen names for this illness used by media, patients, and physicians. They included "twentieth century disease," "chemical injury" and "total allergy syndrome." Today the term "multiple chemical sensitivity" dominates. The acronym MCS is used in several languages.

Some prefer using the broader "environmental sensitivities" or "environmental illness" that also include electrical sensitivities.

People with more severe cases of MCS tend to call themselves the environmentally ill, or EI.

Special interests who want to portray MCS as a psychological problem and distance it from chemicals, created and promoted the alternative term "idiopathic environmental intolerance" (see part 2 of this article).

Symptoms of MCS

MCS is a spectrum disease (Randolph 1990; Gibson 2008; Meggs 2017b). People on the mild end of the spectrum are less sensitive to chemical exposures, have less severe symptoms and can live rather normal lives. People on the severe end of the spectrum are much more affected by even minute amounts of chemicals and have to make major changes to their lifestyles.

Most people with MCS are on the mild end of the spectrum, which is sometimes just referred to as "chemical sensitivity" (Meggs 2017b).

Several other illnesses are also on a spectrum. This includes some infectious diseases, such as COVID-19, that can produce a variety of symptoms and affect people mildly to very severely (Davis 2021). Other examples are migraines, Mast Cell Activation Syndrome, lupus, and autism.

The most common symptoms of MCS are in the central nervous system, such as headaches, clouded thinking (brain fog), dizziness and difficulty concentrating. Other common symptoms are fatigue, body aches, blurry vision, respiratory difficulties, asthma, sinus pain, memory loss, irritable bowels, migraines and more (McCampbell 2011; Sears 2007; Ashford 1998).

The clouded thinking that most people with severe MCS get is aptly referred to as "brain fog." It makes it extremely difficult to perform complex abstract thinking, such as reading and writing. Meanwhile, more basic functions are less affected, such as watching television, light conversation or driving a car (Fiedler 2000)

Brain fog feels like having not slept all night, or even not slept at all for several nights. Brain fog may be caused by a swelling in the brain, when exposed to chemicals (Wardly 2018). But this has not been adequately studied.

For some people, MCS feels like having the flu, but without a fever. It can be a "flu" that gets better on some days and worse on others, but never quite goes away. People have good and bad days, without always knowing why.

The symptoms may be chronic in the winter where we tend to spend more time indoors with closed windows and tightly sealed homes and offices. Some people experience it as having "the flu" for much of every winter.

Symptoms can come shortly after an exposure, or they can be delayed. Inhaled triggers tend to act faster, while ingested triggers tend to be slower (Ziem 1992).

Symptoms from exposures may last just a few minutes, or they can take hours, days or even weeks to resolve. Some people have so frequent exposures they simply feel sick all the time and may not even be sure what causes the symptoms.

Many other symptoms are reported, affecting virtually all parts of the human body. The table below lists how often the major body systems are affected.

Central nervous system	80%
Musculoskeletal	73%
Gastrointestinal	61%
Dermal	56%
Auditory	52%
Mucosal & Respiratory	50%
Polyneuropathy	13%
Cardiovascular	6%

Frequency of affected systems in MCS patients. Source: Lacour 2005.

Some patients can actually taste it in their mouths when they are exposed to chemical fumes.

The many possible symptoms are puzzling, and make some physicians skeptical. However, it is well documented that cigarette smoking can also produce a very wide range of health effects, such as heart disease, low birthweight, stroke, low sperm count, diabetes, arthritis and a dozen types of cancer (CDC 2021). Long covid can produce 203 different symptoms (Davis 2021).

Some people refer to MCS as "odor intolerance." That is misleading, since severe cases can react to chemicals so diluted they cannot be smelled. There are people with MCS who have totally lost their sense of smell, but still react to "odors."

People with MCS can react to chemicals put on the skin or ingested in the food. Chemical fumes can also enter through the eyes (Millqvist 1999).

MCS does not appear to be directly fatal, but there have been several indirect deaths from suicide, asthma attacks, and severe malnutrition. It may also have interfered with the treatment of fatal diseases, such as cancer, due to drug intolerances or a reluctance to seek medical care.

Triggers

There can be just one class of chemicals that triggers symptoms, such as fragrances or pesticides. Or there can be a wide variety of chemicals that cause problems.

In some cases, people start having problems with just a few chemicals and then over time more and more types of chemicals become a problem. This is called "spreading" (Ashford 1998: ch 2).

Common problems are:

- Pesticides
- Fragrances
- Fabric softeners and detergents
- Carpets
- New clothes
- Solvents
- Formaldehyde
- Glue
- Smoke (tobacco, wood smoke, BBQ)
- Vehicle exhaust
- Mold
- Flame retardants
- Alcohol
- Food preservatives
- Artificial food flavors and coloring



Paint is a common trigger of symptoms.

Many other types of fumes can also cause symptoms (Sears 2007; Gibson 2008). However, it is individual what fumes are a trigger. Fragrances are one of the most common problems; three surveys found that it was a problem for 81 to 96% of people with MCS (Steinemann 2018; Caress 2002; Gibson 2008).

Natural chemicals can also cause symptoms, especially terpenes. Terpenes are released from sawn lumber, fresh cut grass, and all sorts of vegetation on a hot day, such as a pine forest.

Essential oils are usually also a problem. These products all contain toxic solvents, even those labeled "natural" or "organic" (Nematollahi 2018).

Newer clothes are a common trigger, especially if they are stain repellent, wrinkle-free, or flame resistant. Work uniforms can be particularly toxic (Wicker 2023).

Alcohol is a natural chemical, which is a problem for many people with MCS, even in very small amounts (Randolph 1990; Bell 1995; Miller 1999; Millqvist 2008), though there are also cases of alcohol addiction (Randolph 1990).

Digestive chemicals, such as artificial flavors, artificial colors, preservatives, and pesticide residues are also common problems (Randolph 1990).

Chemicals have effects on people with MCS at levels far below what is otherwise considered safe. This makes it controversial, but the leadership of the scientific community is gradually accepting that "safe" levels of chemical can still have health effects (Birnbaum 2012).

Adaptation – the masking effect

Complicating things is what in the MCS community is called the "masking effect." It is similar to what is called "adaptation" by physicians.

When a person with MCS is sensitized to a chemical she is exposed to daily, it may not seem to cause any symptoms. Instead, there are just some chronic symptoms all the time, such as headaches.

For example, a person who is sensitive to fragrances may not feel any worse when putting them on in the morning than during the rest of the day. But if she completely abstained from using any fragrances for a week or so (including all scented products) and then tried them again, powerful symptoms may then appear.

Some symptoms may get worse during the time of abstinence, just like they can for people who stop using nicotine, alcohol, caffeine or many other drugs. This is called "unmasking" or "de-adaptation" (Randolph 1990; Ashford 1998: ch 2 &10).

This has also been observed in painters, welders and other workers exposed to chemicals, who get withdrawal symptoms on weekends (Ashford 1998: ch 2).

The scientists who in the early 1990s sealed themselves up in a chemical free "bubble" called Biosphere 2, noticed the same effect. When they came out again, they found vehicle exhaust overwhelming (Nelson 2018).

MCS is a common disease

MCS is surprisingly common. About 15-20 percent of the population has some level of chemical sensitivity. This number may be increasing.

People with more severe cases of MCS comprise 0.5% to 4% of the population, depending on the severity.

Since the World Health Organization has not yet recognized MCS, there is no specific diagnostic code for MCS (though some countries have added their own codes). That means MCS does not show up in the official statistics. Scientists in several countries have tried to estimate how common MCS is by various means. This makes their results less accurate.



Air pollution may be a factor in causing MCS symptoms.

Surveys are the most common method, but the exact wording of the question is very important. If people are asked whether they are simply annoyed by various chemical smells, as much as 33% to 45% of the general population say "yes" (Johansson 2005; Berg 2008).

But annoyance is not illness. Some people just dislike fragrances and other chemical odors, without causing them any real symptoms. This is good to know in the discussion on whether fragrances should be limited in the workplace and public spaces, but does not document how many people live with MCS.

When people are asked whether chemicals or fragrances cause them symptoms, from 8% to 27% say they do. Most of these studies are in the 15%-20% range, though. The studies asked the question in various ways and in different countries, which may explain the outliers.

These studies were done in seven countries: Australia, Denmark, Germany, South Korea, Sweden, Japan and the USA (Kreutzer 1999; Caress 2002, 2004; Johanson 2005; Hausteiner 2005; Berg 2008; Hojo 2008; Katerndahl 2012; Jeong 2014; Azuma 2015; Heo 2017; Steinemann 2018a, 2018c; Miller 2023)

Seventy two prevalence studies in sixteen countries are listed in one article (Palmer 2021).

The trend appears to be rising, with more people affected (Steinemann 2018c).

About 4% are affected so much that they have to make changes to their home, their workplace or what stores they go into (Kreutzer 1999; Caress 2003, 2004; Berg 2008).

The severe cases of MCS comprise about 0.5% of the population. These are the people where the illness imposes major restrictions on their lives, and most can no longer have a job (Kreutzer 1999; Berg 2008).

Since MCS is not an official diagnosis, most studies relied on people's own perception. Few physicians will be comfortable issuing the diagnosis of MCS, but in these studies people were asked if their MCS was diagnosed by a physician:

Location	Diagnosed MCS	Source
New Mexico, USA	2%	Voorhees 1998
California, USA	3%	Kreutzer 1999
Atlanta, USA	3.1%	Caress 2002

Atlanta, USA	6%	Caress 2004
Germany	0.5%	Hausteiner 2005
Canada	2.7%	Park 2017
Japan	0.9%	Watai 2018
Australia	7%	Steinemann 2018c
USA	13%	Steinemann 2018c
Britain	7%	Steinemann 2019a
Sweden	3.6%	Steinemann 2019b

It appears that more physicians were comfortable issuing an MCS diagnosis in 2018 than they were in the years 1999-2005. The widely varying numbers may be due to acceptance in those countries.

Who gets sick with MCS?

MCS is a global problem. In the English-language scientific journals there are articles describing MCS populations in Australia, Japan, South Korea, Indonesia, Canada, United States and several countries in Europe.

There are also articles about MCS in Latin America, such as Brazil and Uruguay (Collares 2006; de Ben 2014).

There was an in-patient MCS clinic operating at the Peking Union Medical College in Beijing, China, already in the late 1980s (Rea 2002: ch 1; Ashford 1998: ch 1).

One large website dedicated to MCS and electrical sensitivity states they each month have readers in more than a hundred countries (EI Wellspring, undated).

About two-thirds of MCS patients are women (Elberling 2009; Johansson 2005; Caress 2004; Eis 2008; Katerndahl 2012; Dantoft 2021).

The percentage of women appears to go up to about 80% when looking at people who seek medical help for MCS or people who are members of support groups (Molot 2014; Gibson 2003, 2016b). This may mean that women are more likely to have the more severe versions of MCS (Hojo 2008).

Why women dominate MCS is unknown. One possible explanation is that since women metabolize alcohol differently from men (NIH 2000), they may also metabolize other chemicals differently. Women's immune system is also different from men's (Wilson 2024).

It is not unusual for diseases to affect one gender more than the other (Watts 2003).

Men are more likely to get lupus nephritis, hemophilia, polycystic kidney disease, autism, type-1 diabetes, cancer, and Lou Gehrig's disease (ALS).

Women are more likely to get Alzheimer's, migraines, celiac disease, drug allergies, autoimmune diseases, lupus erythematosus, fibromyalgia and rheumatoid arthritis (Regitz-Zagrosek 2012; Pincott 2020; Rizzoli 2018; Hisham 2014; Wall 2021; Wilson 2024).

Until about year 2000, it was widely believed that MCS patients were largely "middle-aged white women with above-average levels of education" (Bell 1999; Fiedler 1996; Black 1990). But that was simply because they were the people who were able to realize standard medicine had nothing to offer, and seek out alternatives and join patient organizations.

Research now shows that MCS strikes across race, educational level, social class, and geography (Meggs 1996; Voorhees 1998; Kreutzer 1999; Caress 2002, 2004; Katerndahl 2012; Dantoft 2021; Miller 2023).

The illness mostly hits people older than thirty years (Miller 1999; Katerndahl 2012). However, it can affect people of all ages, even infants (see later).

Working in a profession with exposure to toxic fumes increases the risk of developing MCS. Examples are hair dressers, flight attendants, farmers, and industrial workers. People spending their day in a "sick" building are also at risk, such as teachers, office workers, and housewives (Martini 2013; Watai 2018).

Most people with MCS have a job, though they are also more likely to have stopped working (Dantoft 2021).

People born by caesarean section or have received a high number of vaccinations may also have increased risk (Watai 2018).

There have been some clusters of people getting MCS around the same time, usually from a large exposure. These include a group of workers excavating a new subway line through polluted soil (Davidoff 1998), workers cleaning up the Exxon Valdez oil spill in Alaska (Johnson 2008; Mother Jones 2003), and casino workers exposed to pesticides (Cone 1992; Brazil 1992). A much publicized incident was when a hundred office workers at the US Environmental Protection Agency got

sick when new carpet was installed in their building (Toufexis 1988; Weisskopf 1988). More than a dozen became permanently disabled (EI Wellspring 2019a).

Following the Hurricane Katrina, refugees were housed in 120,000 brand-new trailers with unusually high levels of formaldehyde. Forty-two percent of the children in a study had "respiratory disorders" that may be caused by the trailers (Carmichael 2008).

It appears that people made sick from pesticides tend to have the more severe version of MCS than those sickened by lesser neurotoxic chemicals (Miller 1995).

Other clusters are seen in industries using toxic chemicals (Sparks 1990; Hembree 1986).

Personalities

It is a common myth that a certain "type" of person gets MCS. Anyone who visits with several people who have the illness can easily observe this is not true. Of course, it must be people who have become settled and are not focused on simply surviving, as those newly sick often are, just as it is for people with other disabilities.

Popular media sometimes expect the sick people to be paragons. The reality is that they have the same human flaws as everyone else.

The sick people come from all walks of life. Some are accomplished professors, doctors, lawyers, engineers, scientists, and other professions.

Life expectancy

There are no studies on this, but it appears that people with severe MCS live about as long as regular people and eventually die of similar causes.

There are some suicides. It is hard to know the exact reasons, but in many cases the cause appears to be the living situation. Lack of safe housing or imminent threat of losing a safe house (of financial reasons), seem to be recurrent factors.

Diagnosing MCS

It is difficult to diagnose MCS since there are few objective lab tests available yet and the symptoms can all have other causes. A physician will tend to diagnose MCS based on patient history and by eliminating other possible illnesses (Harter 2020).

Common diseases that might produce symptoms similar to MCS and need to be ruled out include: anemia, diabetes, kidney disease, porphyria, HIV infection, Borrelia infection, dementia, schizophrenia, and several others (Lacour 2005).

Of course, it is possible for someone to have both MCS and one of these other diseases, which will make diagnosing it correctly very difficult.

The most commonly used case definition is the 1999 Consensus Statement, which specifies these six criteria (MCS consensus 1999):

1. A chronic condition
2. Symptoms are reproducible
3. Multiple organ systems are affected
4. In response to low-level exposure
5. From multiple unrelated chemicals
6. Patient improves when removed from exposure.

Some researchers enhance this list by also specifying that the central nervous system must be one of the affected organs, and that the patient must also have a sensitivity to odors (Lacour 2005).

However, these extra criteria may be too restrictive, as there are many cases who are not sensitive to fragrances and do not have central nervous system symptoms (Steinmann 2018; Berg 2008).

The problem with all these definitions is that they are broad and rely on the patient's symptoms and observations, and not on any objective lab work.

Many people with MCS do not look sick and have no visible signs, though some have swollen lymph nodes, rashes, irregular heart beat, swollen hands or feet, or other signs.

Many physicians use lab tests to help them make a diagnosis. Most, perhaps all, lab tests will show normal results. There is no standard lab tests to diagnose MCS, but specialists may check the neurologic, immune, and detoxification systems.

A common problem seen in people with MCS is that the two-phased detoxification system is out of balance, which means toxic compounds can build up in the body (Molot 2014: ch 19). The test involves eating pills with caffeine and other substances and collecting the urine over several hours.

Some physicians may look at the immune system through a count of the white blood cells.

In Japan, neuro-ophthalmologic tests are often used for diagnosing MCS (Mizukoshi 2015).

Other tests may look at how much heavy metals and toxic chemicals are stored in the body. This can be done by blood tests, breath tests, hair tests or fat samples.

There are many kinds of neurological tests, such as walking a straight line blindfolded and a slew of memory tests and intelligence tests.

Most physicians will ask a lot of questions to make the diagnosis. Some use special MCS questionnaires; the most common is the QEESI, which is available in several languages.

Exposing a patient to toxic chemicals is not a reliable test, and is unethical as it puts the patient at risk (Spiegel 2004; Brussels Declaration 2015).

In the end, the diagnosis will be made from the pattern the physician finds and recognizes.

In North America, the physicians who have the expertise to diagnose MCS tend to be members of the American Academy of Environmental Medicine, which has a referral service on their website. In other countries a local MCS support group may be helpful with a referral.

Diagnosing yourself

Attempting to self-diagnose is not reliable and should be done with great caution. The cause of illness may be something different which would not be addressed if mis-diagnosed.

If traveling to a competent physician is expensive or difficult, you can do some experiments on your own to see if MCS is the likely diagnosis before going for a proper diagnosis.

Find a website with the QEESI questionnaire (Quick Environmental Exposure and Sensitivity Inventory). It should give you a good idea whether you have MCS or not.

Try to spend an entire day – morning to sunset – in a big open park. Preferably a park well outside any city and not during pollen season. Take a shower in the morning, but use just water. No shampoo, soap, lotions, makeup or deodorant. Wear old clothes that have been aired out for a week since washing, and not washed using scented detergent or fabric softener. Do not enter any building if at all possible, but stay outdoors all day. Do not sit inside a car either. Bring your lunch and eat it outside.

If you feel much better, that does not prove you have MCS, but you might. The experience can help you experiment further, before going to a specialist.

The cause of MCS

What causes MCS is not known for sure. Canadian MCS specialist, Dr. John Molot suggests (2014):

Our detoxification system has existed for millions of years, but it was not designed to detoxify the hundreds of pollutants to which we are now exposed on a daily basis. Those of us with higher chemical exposures or poorer detoxification systems are even more at risk.

For many years, some physicians stated MCS couldn't possibly be caused by low levels of chemical exposures, since they were "proven" to be safe, but the U.S. National Institute of Environmental Health is starting to question that (Birnbaum 2012).

According to a consumer group, American women put an average of 168 chemicals on their skin every day through personal care products (Lupkin 2015). Whatever is put on the skin will soak in and eventually circulate in the blood.

Two studies found that people who have lived in newly built houses were much more likely to have MCS (Jeong 2014; Watai 2018).

Even newborn babies start out life with hundreds of chemicals in their blood (Goodman 2009). The long-term health affects of many of these chemicals are unknown.

Why some people get sick from everyday chemicals, while others do not, is unknown. It may be because of an underlying genetic weakness, combined with exposure to chemicals, or perhaps combinations of chemicals.



Carpets were one of the products suspected of causing MCS already in the early 1990s.

It is well known that how fast people detoxify chemicals in their system can vary dramatically. Some people can metabolize caffeine forty times faster than others (Yang 2010), while there can be a ten-fold difference metabolizing anti-depressant drugs (Kirchheiner 2007).

Some people get MCS virtually overnight, while for others it is a process that can take years while slowly getting sicker and less tolerant of chemical exposures. A few appear to be born with it.

About 20-30% got MCS after one large chemical exposure, while 40%-60% report the onset came gradually (Gibson 2003; Berg 2008; Terr 1986; Miller 2023).

A general theory is that a person's ability to tolerate chemicals is slowly eroded away and then a threshold is reached, where further exposures can no longer be tolerated and cause symptoms (Miller 1997). This mechanism has been demonstrated using lab rats (Rogers 1999).

The exposures people most associate with causing their MCS are mold, pesticides, new building materials, medical treatments (antibiotics, breast implants, etc.) and fires/combustion products (Miller 2023).

Some suggest pesticides are a major cause of MCS, but it is not that simple. In the Nordic countries pesticides are not used in homes, offices, stores or on lawns, yet MCS is as common there as in pesticide-soaked United States (see earlier data).

There is a large group of women who got sick after receiving breast implants, and some got relief when they were removed (Miller 1999; Ashford 1998: ch 8).

Chemotherapy can sometimes cause an MCS-like intolerance to fragrances and other odors (Bernhardson 2009). Chemo patients often describe having brain fog, which they call "chemo brain" (Gross 2007).

There are more than 85,000 different chemicals in common use. Few have actually been studied to find out if they affect human health. They are considered "innocent" until proven toxic, and proving something is toxic is both technically and politically very difficult (Michaels 2008; McGarity 2008).

The exception is the European Union, which is implementing their REACH rules, where any new chemical must be tested before it can be marketed (EUC 2012). They have an enormous backlog of chemicals that are already in common use, and it will take decades for health improvements to show up in statistics.

It may simply be that the ever-increasing number of chemicals we are exposed to as part of modern life is too much, and some people are more susceptible than others. It may be more complicated, such that a combination of chemicals are more toxic than each chemical alone, an effect that has recently been recognized (Ruden 2019; EUC 2012). In popular media, this is referred to as the "cocktail effect."

There are many theories of what specifically goes wrong in the human body. None of them have been sufficiently investigated to prove or disprove them.

The newest theory is that MCS is a form of Mast Cell Activation Syndrome (Miller 2021).

It may be that since electromagnetic radiation apparently can make the blood-brain barrier leaky (Persson 1997; Eberhardt 2008), then exposures to both EMF and neurotoxic chemicals at the same time might cause changes to the brain (Hardell 2008; Belpomme 2015).

Another theory involves nitrous oxide and the calcium channels in the human cells (Pall 2002, 2013).

Some think that oxidative stress may be a cause (Molot 2014, 2023; Belpomme 2015).



The myriad of chemical products used in the average home may be a cause of MCS, but nobody knows for sure.

The immune system is involved in various MCS theories. Many studies have found abnormal immune systems, but they are not consistent and much more work is needed here (Dantoft 2015). MCS may be an autoimmune disease – more than hundred and fifty have so far been discovered, and 75% of the patients are women, but nobody have tried to look in MCS patients.

Then there is the limbic kindling theory, where MCS is perhaps related to epilepsy (Bell 1999; Gilbert 2001; Ashford 1998: ch 8).

A newer theory, called “central sensitization” suggests changes to the central nervous system (CNS) leading to increased effects from sensory input. There is one human trial to support this theory (Tran 2016)

There are also theories involving how the body breaks down chemicals from the blood stream, especially involving the cytochrome P450 system and NMDA receptors (Ashford 1998: ch 8; Pall 2002; McFadden 1996).

Other theories involve various parts of the olfactory system that senses smells (Greene 2002; Pall 2004; Meggs 1993, 2017a; Viziano 2018).

It may be that MCS is actually a class of illnesses, just as infectious diseases and cancer are classes of diseases. This can explain why there seems to be such a variety in how MCS shows up in different people (Ashford 1998).

Several of these theories are discussed in: (Dantoft 2015; Ashford 1998).

Since the illness is not well understood and no lab test to diagnose MCS has yet been developed, some scientists believe MCS is a psychiatric illness (Bornschein 2002). As support for their theory, they point to the emotional stress many people with MCS exhibit (Skovbjerg 2015). Others say that this stress is simply caused by having their lives upended by a difficult illness, or that the illness directly affects the brain (Randolph 1990; Davidoff 2000; De Luca 2011; Caress 2002).

The same types of distress seen in some people with MCS are also common for people in other stressful situations, such as domestic abuse (Adkins 2010). The social isolation people with severe MCS are often subjected to can also produce the emotional stress seen in some MCS patients (Brooks 2020).

See part 2 of this article for a description of how stressful and difficult it is to live with MCS, and for more sinister reasons why some people strongly promote MCS as an imagined illness.

It is likely to take decades before there is any clarity on the cause of MCS. Meanwhile, this controversy leaves people suffering from MCS in limbo regarding treatments, accommodations, disability acceptance, and insurance coverage. There is an urgent need for science to provide the answers, but no funding is available because of this uncertainty. This is all discussed in part 2 of this article.

Is MCS inheritable?

It is commonly believed in the MCS community that MCS is inheritable, especially if both parents have the illness. For that reason, some women have chosen not to have children (Gibson 1996).

Twins are often studied to find out whether genetics is a factor for an illness. In a large MCS twin study, they did find such a link (Elberling 2009). A Japanese study found that MCS does seem to run in certain families (Watai 2018).

There have been a few attempts to look for an "MCS gene," but so far no success (see later).

Various other traits and histories also point to heritability (Bell 1999; Watai 2018).

Overlap with other diseases

There seem to be overlaps with several other illnesses, some of which are also poorly understood.

Allergies

In popular media, MCS is often referred to as some kind of allergy, but it is not. Traditional allergies are defined as being IgE-mediated, and MCS does not use the IgE mechanism (Elberling 2005, 2007; Randolph 1990; Ashford 1998).

People with MCS are much more likely to have allergies and dermatitis than the general population, but not everyone with MCS has allergies (Elberling 2005, 2009; Caress 2003; Hojo 2008; Katerndahl 2012; Jeong 2014).

The more allergies a person has, the more likely it is that fragrances are a problem also (Elberling 2009).

Dr. William Rea reports that 80% of his MCS patients have food allergies (Rea 1988). Dr. Rea saw some of the most severe cases of MCS, so the rate of food allergies may be lower in the overall MCS population.

Two Italian studies found 73% to 92% of people with MCS also have metal allergies, often to several metals (Guzzi 2018; Pigatto 2013).

Asthma

Asthma is an inflammation of the airways, which can be caused by pollen, dust, mold, smoke, perfume, and other irritants. In some people it can be a direct manifestation of MCS, while in others it is not (Ashford 1998).

Asthma is very common among people with MCS, and those who have both diseases tend to be more affected by pollution (Kreutzer 1999; Caress 2004; Berg 2008; Elberling 2005, 2009; Katerndahl 2012; Watai 2018; Steinemann 2018c, 2019b)

Chronic fatigue syndrome/myalgic encephalitis

Chronic fatigue syndrome/myalgic encephalitis is a poorly understood illness, like MCS. A general study found that 28% of people with MCS also had CFS (Caress 2003), while a study of patients at an MCS clinic found 70% also had CFS (Loria-

Kohen 2017). This overlap has also been noted elsewhere (Gibson 2011; Molot 2014; Park 2017; Watai 2018).

Fibromyalgia

Fibromyalgia is another poorly understood illness. A general study found that 22% of people with MCS also had fibromyalgia (Caress 2008), while 65% of patients at an MCS clinic had fibromyalgia (Loria-Kohen 2017). This overlap is also noted by others (Gibson 2011; Molot 2014; Park 2017; Watai 2018).

Autism

Autism is an illness with a wide range of symptoms and severities, just like MCS.

People with autism usually have "sensory oversensitivity," where they are troubled by smells, such as perfumes, loud noises, bright lights, etc (Grandin 2015; Heilbrun 2015).

A study of autistic adults in three countries, found that 84% reported health effects from fragrances. Of these, 43% got migraines, 45% respiratory problems and 36% asthma attacks from fragrances (Steinemann 2018b).

Autism is more likely in people with MCS (Katerndahl 2012). Parents with MCS are three times more likely to have an autistic child than parents who do not have MCS (Heilbrun 2015; Palmer 2024). The risk increases for people with more severe MCS (Palmer 2024).

MCS and autism appear to share some underlying characteristics as well (Wardly 2018).

Migraines

Many people with MCS who also have migraines report their migraines can be triggered by chemical exposures. This connection has not been studied much (Steinemann 2018b).

Migraines can have a variety of causes, but in many cases the cause is not known (Rizzoli 2018).

Electromagnetic hypersensitivity

People with electromagnetic hypersensitivity (EHS) are affected by low levels of radiation from power lines, cellular base stations, wireless networks, mobile phones, etc. The disease is also known as EMR syndrome.

In surveys of people who reported they had MCS, from 7% to 52% said they also had EHS (LeRoy 1996; Levallois 2002; De Luca 2011; Palmquist 2013; Loria-Kohen 2017; Watai 2018; Belpomme 2020).

The higher percentages were seen in patients attending MCS clinics (De Luca 2011; Loria-Kohen 2017; Belpomme 2020). This may be because they are the sicker people in general. It does appear that EHS is more common in people with severe MCS than in those with mild MCS, though this has not been studied directly.

Some scientists speculate that MCS and EHS are two aspects of the same disease (Belpomme 2015; Brussels Declaration 2015).

Electromagnetic hypersensitivity is a newer phenomenon. It first got some attention in the 1980s when computers were introduced in many offices. It also trails behind MCS in scientific understanding and acceptance.

Sensitivity to noise

It has also been reported that people with MCS tend to be more sensitive to noise (Bell 1995; Miller 1994, 1999; Palmquist 2014; Viziano 2016, 2018; Wardly 2018).

An Italian study found that people with MCS process sound abnormally, which might explain the problem (Micarelli 2016).

Gulf War syndrome

Tens of thousands of veterans who returned from the 1990-1991 Gulf War had symptoms similar to MCS, and they did not disappear over time (Miller 1999).

The cause of this illness is still not known, though it is thought that exposures to burn pits and various toxic chemicals, such as pesticides, chemical weapons, and drugs given to supposedly protect against chemical weapons were the cause.

The veterans were widely dismissed as suffering from post-traumatic stress (PTSD) (Showalter 1996; Miller 1999).

Depression and anxiety

Living with chronic illness of any kind tends to make people anxious and depressed.

A large Canadian study found that 19% of people diagnosed with MCS had depression or some other mental disorder (Park 2017)

This is similar to people who face other chronic or life-altering diseases, or forced social isolation (Niedzwiedz 2019; Walker 2013; Brooks 2020; Moyer 2021). Exposure to toxic chemicals can also cause depression by itself (Ross 2010).

There are several studies showing higher rates of anxiety and depression, but they are not reliable. They are all much smaller studies, and included mostly people who were under high stress (recently became disabled by MCS; interviewed by hostile physicians hired by insurance companies, etc).

Other overlaps

Other diseases that tend to overlap with MCS are hypothyroidism, irritable bowel syndrome, lupus, reactive airway dysfunction syndrome (RADS), and post-traumatic stress disorder (PTSD), (Gibson 2011b; Molot 2014; Katerndahl 2012).

Children

Children can get MCS too, but there is very little medical information available.

Children with MCS appear to have symptoms that are similar to adults (Inomata 2006). But there can also be more subtle effects, such as learning disabilities, ADD/ADHD and behavior problems (Rapp 1991, 1996; Randolph 1990).

There does seem to be an association between MCS, autism and ADHD (Heilbrun 2015). The rates of childhood asthma, autism and ADD/ADHD have greatly increased along with the use of chemicals in the home. It is compelling to think there is a connection, though this has barely been studied.

In 1985 and again in 1997, the American Academy of Pediatrics issued statements about problems children can have with synthetic dyes and other additives in medicine and food (AAP 1997).

Full-blown MCS appears to be rare in children, but nobody has studied this. This writer has seen a couple severely sick children at a large MCS clinic and some adult patients have stated they've had MCS as far back as they could remember. There are some written case stories available (McCormick 2001; Inomata 2006; Randolph 1990; Wicker 2023).

MCS can hit infants and very young children (Farrow 2003; Inomata 2006).

In rare cases, children can become so sensitized they cannot be in the same classroom as other children, due to their personal care products, use of ink pens, etc. (Soderholm 2011; Inomata 2006).

In a few cases the parents have been able to convince the other parents to stop the toxic onslaught, but this is often met with resistance and sabotage.

Some parents had to take their child out of the school and either find a private school or homeschool. Some private schools, such as Montessori, tend to have parents and teachers who are more open-minded and not so much into the toxic lifestyle to start with. We know cases where moving the child to such a school worked.

Diagnosing a child with MCS is difficult. A detailed patient history is necessary and the child may not be able to provide enough detail, especially observations that certain exposures are followed by certain symptoms. Pediatrician Doris Rapp has observed that many of these children have red cheeks, red ears and dark circles under their eyes (Rapp 1991, 1996). This is also reported in case stories (McCormick 2001).

Since MCS is controversial, some pediatricians may insist it is psychological and caused by overanxious parents (Woolf 2000).

Treatments

Since MCS is still controversial there is virtually no funding available to study how to treat MCS. What is available is what individual physicians have found sometimes helps through experimentation over the decades (with some actual studies published). There is no standard treatment (Harter 2020).

There is no magic cure, but a variety of treatments that help some and not others. People can spend years and lots of money trying the various treatments and get no relief, while others get lucky and suddenly find major improvement. An experienced and knowledgeable physician can help as a guide, based on her experience and some lab tests, but it is still trial and error. The illness is still not well understood and there seems to be great variety in how it unfolds.

Some patients are not able to find or afford a knowledgeable physician and instead rely on information on the web and social media. Be very careful with such information; there are a lot of echo chambers and people who promote half-baked ideas with great confidence.

Sometimes a particular treatment becomes popular for a while and then fades away again. There have been several such cycles in the MCS community (Evans 2019: ch 1). The same pattern happened in the past with other diseases before reliable treatments became available, such as for tuberculosis and AIDS.

The most important thing to know is that what helps is individual, and what helps one person may not help another.

Also, even if a treatment helps to the point that chemical exposures no longer produce symptoms, doesn't mean the illness is gone. Some physicians say it is never gone, and people who do get better will forever have to be careful with chemicals (Belpomme 2020).

In the following we list some of the most long-lived treatments. This is not an endorsement, which we do not have the competence for. Please discuss them with a competent health provider first.

The most fundamental treatment is avoidance. This means reducing the amount of toxic exposures in daily life from personal care products, laundry products, all sorts of fragranced products, paints, solvents, smoke, pesticides, air pollution and more. Removing them from your life is a process that takes months of effort, as these chemicals are in almost everything in the home, including clothes, carpets, furniture, and electronics. They can also be in the water you bathe in, and thus inhale as droplets or steam.

Living completely free of chemicals is no longer realistic, and probably not necessary. But the load can be dramatically lowered by making choices on what products to use.

Without lessening the load, there is little hope of getting better. It is consistently rated the most effective treatment (Miller 1995; LeRoy 1996; Kosta 2000; Gibson 2003; Martini 2013; Italian consensus 2019).

In two surveys of physicians not specializing in environmental illnesses, strong majorities (82% and 86%) recommended patients avoid troublesome chemicals (Skovbjerg 2009b, Gibson 2011). That is just common sense.

Another part of avoidance is looking at the diet. Processed foods are often loaded with chemical additives, some of which are not listed on the packaging. There can be various preservatives, artificial flavoring, flavor enhancers, coloring, ripening agents, pesticide residues and more. The packaging can also add chemicals to the food, such as from the lining of cans.

Many people with MCS eat organic food as much as possible, and cook their own meals from scratch. Eating such a diet significantly reduces the pesticide levels in the urine in just a few days (Fagan 2020; Hyland 2019; Rea 1984).

Many people have gotten a lot better from simply removing petrochemicals from their surroundings and their diet (Randolph 1990; Ziem 1992; Rea 1984; Gibson 2003). That should be the first step before going further.

Some people have found that oxygen helps them recover from chemical exposures and may even use oxygen while traveling by car or airplane (contact airline in advance). The simplest way is to use an oxygen mask; there are non-toxic ceramic versions available. As a part of a treatment program, some people use hyperbaric chambers with pressurized oxygen.

Sauna therapy is used to remove chemicals stored in the body through sweating, while taking specific supplements to help with the process (Randolph 1990; Rea 1996, 2002; Cecchini 2006; Molot 2014)

Sauna treatment should, at least initially, be supervised by a physician to make sure it does not overstress the liver. Sauna treatment temporarily increases the levels of chemicals in the blood, as the chemicals are transported to the lungs through the blood stream which for most people would temporarily increase their symptoms (Rea 1996, 2002). The same effect is seen in people who are losing weight rapidly (Walford 1999).



Sauna treatment area at a major MCS clinic in the United States.

Some patients report they can smell the chemicals evaporating from their sweat and get increased sensitivities while doing the program. Then they feel better after the program ends (Evans 2010).

Removal of mercury amalgams in the teeth is often done, especially if the level of mercury in the blood is elevated.

Most people with MCS have food allergies – often without knowing it (Rea 1988). They may benefit dramatically from identifying the foods they are allergic to and then avoiding eating them, or at least eating them infrequently. There is no standard list of foods to avoid, it is all individual. They tend to be foods eaten on a daily basis and especially those that are craved. (Someone who craves ice cream every day may be allergic to milk and sugar, for instance.) Some people need to rotate their foods, so they do not eat the same ingredients every day (Randolph 1990).

Various supplements may also be used, especially for reducing oxidative stress and promoting detoxification (Molot 2014).

The Annie Hopper DNRS "brain retraining" program is specifically designed for MCS and has helped many.

Despite that many skeptical physicians recommend psychiatric and psychological treatments, science shows they are rarely effective (Gibson 2003; Kolk 2004; Hauge 2015; Ashford 1998: ch 10; Miller 1995).

Some physicians have caused harm by instructing the patient *not* to avoid chemical triggers in a misguided attempt to "de-sensitize" (Ziem 1992).

It is not surprising psychiatry and psychology have such poor track records, since MCS is not a mental disorder. Unfortunately, some physicians still believe it is.

However, psychotherapy can sometimes help patients *cope* with chronic illness (Hauge 2015). In a large survey, 65% of 362 patients found psychotherapy helpful for coping with MCS (Gibson 2003). The same study found psychotherapy not effective for *treating* MCS.

Various drug therapies also show poor results – and can be harmful (LeRoy 1996; Gibson 2003; Swoboda 2006). There are only a few case reports of positive results from drug treatments (Andine 1997). Drugs appear to only offer "symptom treatment" and not any help with the actual problem.

People also experiment with holistic therapies, such as acupuncture, yoga, meditation, herbs and many other methods. There are myriad of alternative treatments available, with new ones showing up with much promise and older ones fading away again. Gibson (2003) lists 101 treatments in her survey, and that is still not a complete list for today.

The treatments are rarely covered by health insurances, which means they are often only available to the more affluent people.

Critics correctly point out that there is not enough scientific research on these treatments, though the same critics recommend psychological treatments with nearly no science to support them either (Ashford 1998: ch 10).

The problem is that there is no research funding available, because MCS is still controversial (see part 2). But sick people are not an academic problem once it becomes personal. Should a physician tell someone sick with MCS "sorry, we have some good ideas that seem to help some people, but you're gonna have to wait twenty or thirty years until more studies can be done, assuming they can get funded"?

People who are sick need help now. Throughout history physicians have tried to help the best they could with whatever tools they had. This is not new with MCS. The Oscar-winning film *Dallas Buyers Club* vividly describes this issue for the AIDS crisis in the 1980s.

Even today's mainstream medicine relies to a large degree on "common practices" that are not actually based on science (Hardern 2003; Rizzoli 2018).

Do people get better?

There is very little data on this. In the largest study, they found that after five years only 14% were symptom free. Another 17% felt so much better they generally lived a normal life style, but still had symptoms (Skovbjerg 2015).

These studies did not ask people whether they did any treatments or not.

There is no data on how many people with severe MCS got better.

Working on objective tests

The diagnosis of MCS is currently mostly based on symptoms and patient history. This makes it difficult to diagnose correctly and leaves room for those who keep insisting MCS is an imagined illness.

Many studies have simply relied on whether people believed they had MCS (self-diagnosed) or considered themselves "unusually sensitive" to fragrances. There are many other diseases that can appear to be MCS, but are not (Lacour 2005).

If people who do not have MCS are included in the "MCS group" for a scientific study, that can make the study misleading. It can dilute the findings, so they do not appear significant. This is also a problem with other ill-defined illnesses, such as chronic fatigue syndrome (Tuller 2018).

Even the most recent review (Viziano 2018) does not state which studies screened out people with other illnesses. It does not appear to be many – in a limited search we found just a few (Orriols 2009; Viziano 2016; Micarelli 2016; Irigaray 2018; Fiedler 2000; Hillert 2013), but there could well be more.

Since there is such a difference between mild cases and severe cases of MCS, studies should focus on the severe cases as they may have more pronounced objective signs and genetic factors. Unfortunately, the recruitment of subjects seems to target the milder cases of MCS. The severe cases might be more reluctant to participate since many of these scientists do not seem willing to accommodate their needs for non-toxic facilities (especially the psychiatrists, who obviously don't believe that to be necessary).

Finding objective lab tests that can reliably identify who has MCS and who does not is of paramount importance. It will help doctors diagnose their patients, it will help scientists looking for a cure, and it will help gain acceptance of MCS as "legitimate."

Funding is extremely limited, but some important work has been done. Most took place in Europe, since MCS is taken more seriously there than in the United States.

Scientists in Spain, Italy and elsewhere have used brain scanners to discover differences between people with MCS and healthy people (Ross 1999; Hillert 2007, 2013; Orriols 2009; Chiaravalloti 2015; Belpomme 2015; Alessandrini 2015; Azuma 2019).

Ultrasound brain scanning has shown much promise for diagnosing MCS, along with electrical sensitivities (Belpomme 2015; Irigaray 2018; Greco 2020).

Polish and Italian scientists are investigating using breath analyzers to diagnose MCS (Mazzatenta 2021).

Japanese, Danish and French scientists found that people with MCS tend to have chronic low-grade systemic inflammation, which shows up in blood tests (Dantoft 2014; Belpomme 2015; Kimata 2004).

Four studies have found that exposure to toxic chemicals, such as fragrances, can cause people with MCS to release histamine through a different process than the traditional allergy IgE mechanism (Tannenbaum 1982; Elberling 2007; Kimata 2004; Belpomme 2015). Unfortunately, antihistamine drugs do not help.

Several studies have found immune system abnormalities, but the findings are not consistent and much more work is needed (Dantoft 2015).

There is one case report where exposure to fragrances caused a significant increase in a patient's spinal fluid pressure, which appeared to be caused by swelling of the brain. Relieving the pressure removed the brain fog (Wardly 2018).

There have also been experiments in Japan testing the autonomous nervous system by measuring how fast the pupils dilate and constrict, as well as the heart rate variability (Shirakawa 1991; Andersson 2015; Mizukoshi 2015).

Studies have been done in Canada, Japan and various European countries to look for genetic markers for MCS, but so far with modest success (McKeown-Eyssen 2004; Eis 2008; De Luca 2010, 2011, 2014; Berg 2010; Dantoft 2015; Cui 2013; Loria-Kohen 2017)

It may be that the problem is spread out on several genes, which would make it difficult to pinpoint. For comparison, a person's height is influenced by more than seven hundred genes (NIH 2020).

Canadian researchers have identified genes for "heightened somatic awareness" (Khoury 2019). This may also involve MCS.

A large French study explored other biomarkers for MCS (Belpomme 2015).

There are about fifty published studies where people with MCS were exposed to some sort of chemical. The first was done in 1963, where three patients were

exposed to food and water that was either stored in glass or plastic containers (Kailin 1963). Another early study used the air from a "sick" building (Molhave 1986).

There have even been tests exposing heart patients to chemicals they are sensitive to, which induced irregular heart beats (arrhythmia) (Rea 1978).

Such provocation tests are very difficult to do well, as there are many ways to confound the results. In most cases it is all based on symptoms, which can be affected by delayed reactions, adaptation ("masking") and many other factors (Miller 1997; Kailin 1963; Bell 1999). It may be that the testers could smell the difference between "good" and "bad" air, despite efforts to conceal it (Das-Munshi 2006). It could also be that the testers reacted to the staff or the testing room itself, which is a critical factor very few of the experimenters even consider in their reports.

It appears that the specific chemicals used are much more important than the concentration in the air (Mizukoshi 2015). And that mixtures of chemicals are much more potent than the chemicals tested separately (Cometto-Muniz 1997)

There is also the question how representative the test subjects are of the general MCS population. The more sensitive may decline participating, since the impact of the exposure may be severe and long lasting. Also, since most of these tests were done by psychiatric researchers, some potential test subjects may be skeptical of possible biases and decline to participate. And since psychiatrists tend to be biased towards believing MCS is psychosomatic, that also seem to affect how well they do their studies.

It is also important to screen out participants who are traumatized by their illness, as they are unlikely to be reliable testers. Very few of their studies did.

It is well documented that a similar group, people who do chemo therapy, also are very poor at identifying placebos (Monvoisin 2019; Fielding 1983).

Some of the newer tests have used odorless gasses, such as capsaicin (Millqvist 2008; Ternesten-Hasseus 2013). Others have used a "masking odor," but then some people with MCS got sick from that alone – which critics misinterpret as a reaction to the "inert" placebo (Das-Munshi 2006).

These studies have not been a boon for understanding or "proving" MCS. Predictably, the two camps interpret the results very differently (Das-Munshi 2006; Goudsmit 2008; Viziano 2018).

Several scientists have called for a halt on doing such experiments (Spiegel 2004; Brussels Declaration 2015).

A few groups are working on putting together new diagnostic criteria for MCS, but it will take time to get them completed, validated and accepted (Damiani 2021; Italian Consensus 2019; Belpomme 2020).

A fundamental difficulty may be that MCS is not just one disease, but a class of diseases, just as "infections" is a class of diseases that has not just one set of diagnostic tests (Miller 1997).

Part 2 of this article

The second part of this article covers the impact of the illness on people's lives, such as at work, at home, and when using the health care system. We also cover the reasons why there is such a lack of funding for research, why the illness is still controversial, and the human cost of the controversy.

Part 2 is available at

www.eiwellspring.org/health/IntroductionToMCSpart2.htm

More information

Additional information on how people cope, personal stories, the controversies, and more is available on www.eiwellspring.org/intromenu.html.

References

The references to this document are available at

www.eiwellspring.org/health/IntroductionToMCSreference.htm

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