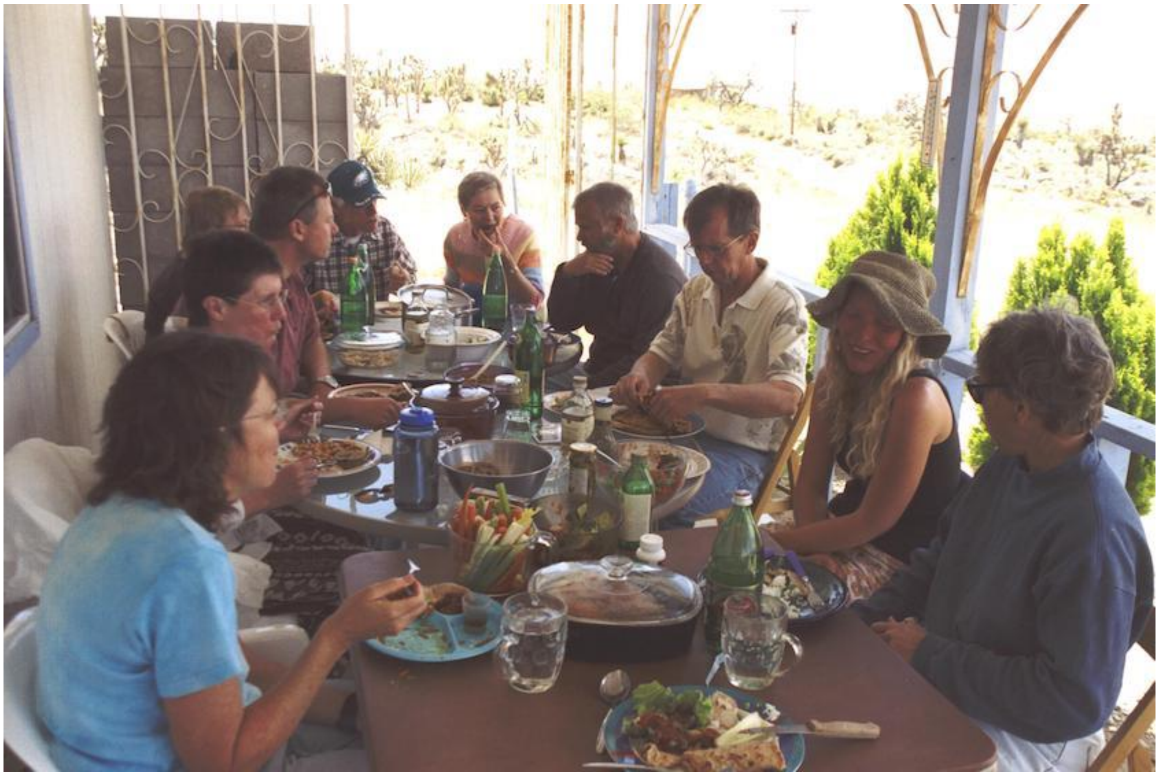
Multiple Chemical Sensitivity

Part 2: Impact and coping



This is the second part of a comprehensive overview of MCS, where we cover what it means to live with this illness, the resistance to accepting it and the human cost.

Keywords: multiple chemical sensitivity, MCS, impact, lifestyle, community, resistance, controversy, health care, pharmaceuticals

In the first part of this article we described what is known about what causes MCS, what the symptoms are, who gets it and some of the treatments. This part is available on www.eiwellspring.org/health/IntroductionToMCSpart1.htm.

Fragrances

Fragrances are one of the biggest problems for people with MCS. They are virtually everywhere, in nearly all personal care products, cleaning agents, and laundry products. They are widely used as so-called "air fresheners" (though they do not in any way clean the air). They are added to products such as clothing and toilet paper. They are heavily promoted in advertising; many people can't imagine themselves without "their scent."

Some of us old-timers remember there was a time when restrooms were rarely fragranced. Then in the 1990s fragrance dispensers for restrooms were heavily marketed and quickly became the norm.

One reason fragrances are so heavily used in many consumer products, such as shampoos and cleaning agents, is to overpower the unpleasant smell of the product itself. Even products marked as "unscented" may have a "masking scent" to cover the actual smell of the product (Grenville 2017; Steinemann 2009; CCOHS 2020).

Fragrances make it difficult or impossible for people with MCS to visit many stores, theaters, restrooms, schools, offices, public transportation, laundromats and other public places (Soderholm 2011; Steinemann 2016; Larsson 2009).

Fragrances are also commonly used in health care facilities, making them hazardous for people with MCS. They are even used in anesthetic gases for surgery (Sato 2019). The fragrance industry reported an increasing use of scented products in the American health care field, though some hospitals have a no-scent policy (Keen 2012).

Fragrances can contain hundreds of different chemicals, many which have not been tested for health effects, and some that are known to be hazardous or toxic. But in most countries fragrances are exempt from regulation and the producers do not have to disclose their ingredients. What information is disclosed reveals little of the actual content and is sometimes misleading (Grenville 2017; Steinemann 2009).

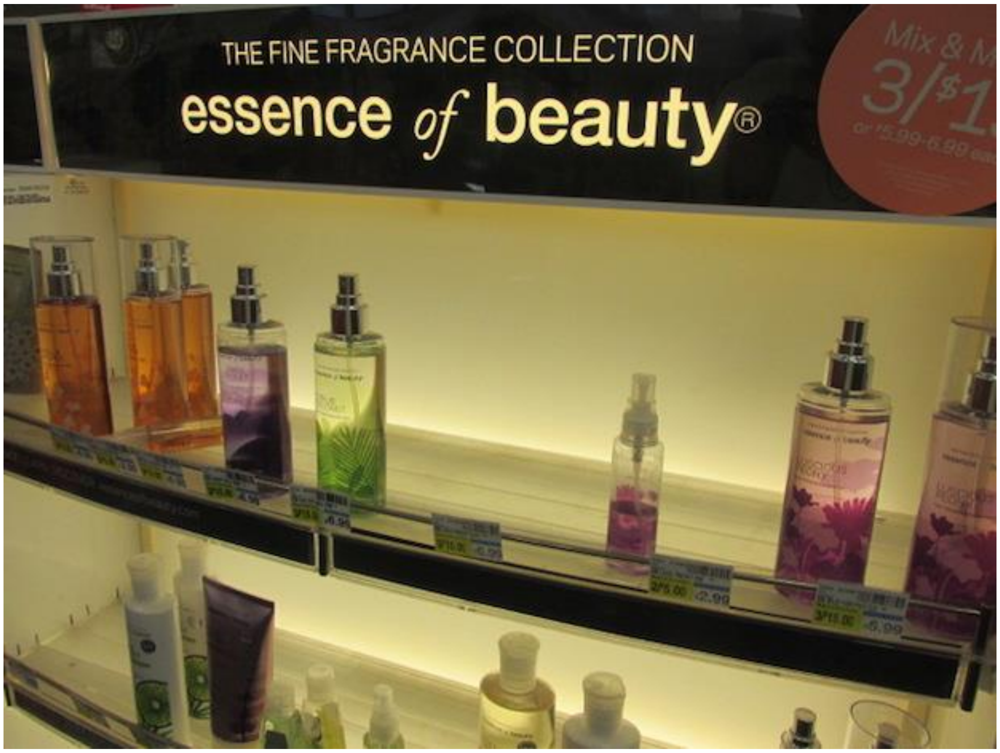
It is no wonder fragrances are consistently one of the top problems facing people with MCS (Kosta 2000; Steinemann 2016, 2018a, 2019; Berg 2008; Larsson 2009; Lacour 2005; Dantoft 2021).

Asking people if they get symptoms from fragrances is sometimes used as a simple substitute for whether people have MCS (Elberling 2009).

A British study found that infants exposed to fragranced products were more likely to have diarrhea, vomiting, and earaches (Farrow 2003).

A Danish study found that people with fragrance sensitivity had much higher levels of histamine in their blood than healthy controls, when exposed to the Yves Saint Laurent perfume Opium (Elberling 2007).

People have been hospitalized after attacks with fragrance sprays (L.A. Times 1989; Lessenger 2001).



Essential oils are often touted as "natural," and there are even some that are labeled "organic." But an analysis of 25 essential oil products found that 100% of them contained toxic chemicals – even those labeled "organic." Acetone and acetaldehyde were each in 90%, and toluene in 50% of the products (Nematollahi 2018).

Predictably, there is fierce resistance to restricting fragrances in public places. A spokesperson for the Monell Chemical Senses Center call fragrance sensitivities "anxieties" and that "health care professionals themselves can over-sensitize patients into believing they will have a reaction to fragranced material..." (CMAJ 2011). The Monell Center's website states they have over fifty corporate sponsors from the food, beverage, fragrance, pharmaceutical and chemical industries (Monell 2020). Despite these ties, they claim they are "independent."

Activists have tried to limit the onslaught for decades, but found that the fragrance industry has a lot of clout (Hamilton 1994).

Pesticides

The various forms of pesticides are often a major problem for people with MCS, sometimes even years after they were applied.

In the 1980s and 1990s several people got sick from pesticide treatment of their homes with products that were claimed to be "safe" and "EPA approved," but were later taken off the market because they were too dangerous (Berkson 1998).

Since pesticides are all designed to kill life, it is doubtful that any of them are safe for people with MCS.

Pharmaceuticals

Drugs and nutritional supplements can cause trouble for people with severe MCS (Randolph 1990; Heilbrun 2015; Niedoszytko 2006; Inomata 2006; Swoboda 2006; Miller 1999; Ziem 1992).

Drugs are commonly a problem for people with MCS.

In one survey, nearly half of the people with MCS also reported sensitivity to at least one drug (Palmer 2020).

In two patient surveys, drug treatments for dealing with MCS symptoms were reported as more harmful than helpful (Gibson 2003; LeRoy 1996).

The problems are not well studied, but there are various theories. Since many people with MCS have problems detoxifying chemicals, the normal drug doses may be too high as they are not broken down as fast as expected. Some people are able to use drugs at a much lower than normal dose.

The drug is actually a small part of what is in a pill. Most of a pill consists of so-called "inactive" ingredients:

- Preservatives
- Fillers
- Binders
- Flavoring/sweeteners
- Coloring
- Lubricants

These can cause problems for people with gluten intolerance, lactose intolerance and other sensitivities (Reker 2019; Inomata 2006; AAP 1997).

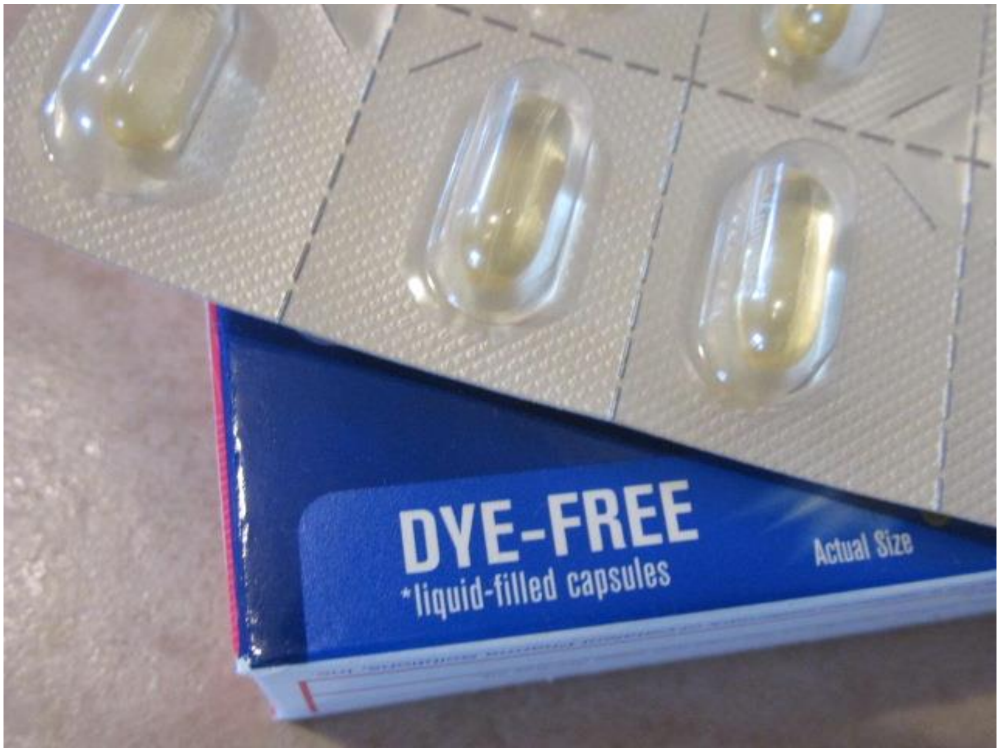
Dr. Theron Randolph found that some of his MCS patients had no problem with drugs in their pure form. It was only when bought commercially with all the additives (Randolph 1990).

Some people experiment with different brands of the same drug to find one with a more tolerable combination of additives. Of course, the manufacturer may change the additives without warning, or stop making the drug.

Using a compounding pharmacy can cut out a lot of the additives, but it costs more and is not always a solution.

Liquid pharmaceuticals usually contain a preservative. Many report stinging or itching when using regular eye drops. When pharmaceuticals are injected there can be stronger symptoms, due to these preservatives. An example is conventional allergy shots with the preservative phenol (Randolph 1990; Evans 2010).

The medical literature describes similar drug intolerances in other patient groups that are seemingly unrelated to MCS (Molderings 2016; Hisham 2014).



Dyes and other additives in drugs can cause symptoms in people with MCS. It may not be the drug itself.

Drugs are the foundation of most physicians' practices. This fact alone may be why many physicians are skeptical of drug intolerances and often mis-label sensitive people as hypochondriacs. Doctors are humans too.

Health care

People with MCS get the same illnesses other people get, and thus need the same access to health care.

The health care system is the one institution of society where people struggling with severe illness should be able to go and be taken seriously and not be further harmed, but it often fails at that (Gibson 1996, 1999, 2003, 2005, 2016c; Kroll-Smith 1997; McCormick 2001; Lipson 2004; Dumit 2006; Swoboda 2006; Eek 2009; Kosta 2009; Skovbjerg 2009a; Evans 2010; Soderholm 2011; Molot 2014).

Traditional doctors have little to offer beyond drug treatment, and drugs are sometimes harmful to people with MCS and rarely helpful (see section about pharmaceuticals). This leaves both doctors and patients frustrated. Some patients even get labeled as "uncooperative" (Swoboda 2006).

Another frustration is that doctors do not have a diagnostic code for MCS, which can cause trouble with billing and insurance bureaucrats – and is a crucial token of legitimacy (Dumit 2006).

Few physicians have any training in treating MCS so patients are left to go from doctor to doctor to find one who understands the problem and doesn't just brush it off. In a survey of 917 MCS patients, they reported trying a mean number of twelve physicians (Gibson 2003).

Patients with MCS are often ignored, told MCS doesn't exist, or falsely given a psychiatric label when attempting to use the medical system (Lipson 2004; Swoboda 2006). One patient in the United States stated:

> *They're very dismissive and you hear them talk about you in the hallway, you see them rolling their eyes, oh yeah the woman in there with all the chemical things* (Gibson 2016c).

A patient in Denmark stated:

> *In my experience, dealing with the healthcare system has by far been the worst part in all of this. The suspicion they cast on you. How can you possible treat people like that?* (Skovbjerg 2009a).

Some were even sent to psychiatric hospitals (Gibson 1996c). In Australia, some were forcefully taken from their homes and involuntarily committed to a psychiatric hospital (Crumpler 2014). Laws now prohibit this in the United States, but just a few decades ago such actions were taken against people who were gay (Faderman 2015).

A Canadian physician wrote:

> *Most patients with the pattern who come to environmental health clinics are frustrated. Multiple physicians have reassured them that nothing is wrong ... Patients come away from their doctor's office feeling they have been told that it's all in their heads and they should suck it up* (Molot 2014).

People with fibromyalgia, autoimmune diseases, and chronic fatigue syndrome also report being ignored, disbelieved and psychologized by physicians (Doebl 2020; Gibson 2005; Konnikova 2021; O'Rourke 2022).

The book *How doctors think* describes a woman with celiac disease (wheat intolerance). She went from doctor to doctor for many years and they kept mis-labeling her as bulimic/anorexic and insisted she eat as much wheat pasta as possible, since she kept losing weight. She nearly died (Groopman 2008: ch 1).

There are many stories floating around the MCS community about how the doctors failed the MCS patient. This has created a distrust that carries over to other areas of health care, since if the doctors won't take MCS seriously then how to trust they will take it into consideration when treating other illnesses? (Kosta 2009).

In one study, only 9 people out of 121 reported visiting physicians who respected their account of MCS (Kroll-Smith 1997 p 96). In another study, all 19 participants stated that they avoided conventional medical care unless they had an emergency (Gibson 2016c).

The situation does appear to be slowly improving. Today's physicians seem to be more accepting of MCS and more willing to accommodate the patient's needs in small ways (Cooper 2007; Skovbjerg 2009b; Gibson 2011a, 2016b).

This may be because of a generational change, with physicians having heard about MCS at a younger age. And the most outspoken anti-MCS physicians of the 1980s and 1990s are no longer active.

It may just be that today's physicians humor MCS patients in order to have a better doctor-patient relationship and avoid possible lawsuits, as advised by an Australian anesthesiologist, who is dismissive of MCS (Fisher 2008).

When people with MCS cannot avoid the medical system and may need surgery, they tend to ask more questions than regular patients:

> *Many practitioners find such inquiry intimidating or view the patient as demanding or hypochondrial, when in fact the patient in need of an operation or special procedure only wishes to avoid an adverse reaction ... When they must place themselves in the hands of the medical establishment, chemically sensitive people feel a lack of control and a vulnerability most would not understand* (Ashford 1998: ch 3).

Nurses tend to be more sympathetic and less dogmatic; perhaps because MCS is portrayed with sympathy in nursing journals (Cooper 2007; Larsson 2009; Gibson 2011a, 2016c)

Or maybe it is just because nurses tend to be more pragmatic.

Many clinics and staffs are still fragranced or otherwise unsafe. Sometimes MCS patients have to wait outside instead of in the waiting room, regardless of the weather. The appointment itself may have to be outdoors (Sledd 2010; Gibson 2016b).

Fragrance-free policies are becoming more common now, which is a great help. But it was really slow in coming, and there is still much resistance (CMAJ 2011; Keen 2012).

When a person with MCS needs to be hospitalized, it is best to bring a friend who can be a patient advocate and stand up to the physicians. This writer once was part of a group watching over an MCS patient in a coma and had to stand up to an arrogant physician (a hospitalist) who insisted on injecting a dangerous and unnecessary drug solely for their convenience. Fortunately the ICU nurse refused to follow the doctor's order. The physician left in a huffy (the patient made a full recovery).

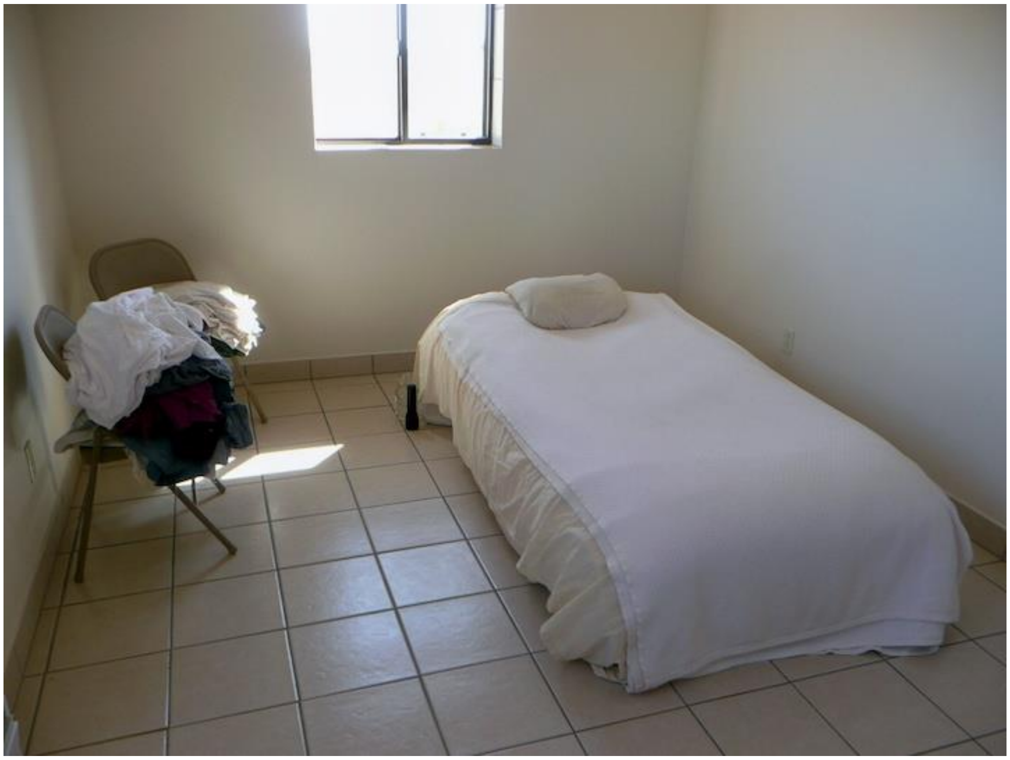
Housing

It is a fundamental need that one's home should not cause major symptoms. For people with severe MCS that is often an enormous problem. Modern houses are built of many kinds of problematic materials, such as manufactured wood boards (plywood, OSB, particle), gypsum wallboards, carpets, paints, caulks, fiberglass, vinyl and much more. Then they tend to become contaminated with fragrances, pesticides, laundry chemicals, cigarette smoke and mold.

Living in an apartment is extra difficult, since the walls are not airtight. The neighbor's fragrances, tobacco smoke and laundry fumes can enter through the walls and open windows (Soderholm 2011; Evans 2010). A shared enclosed stairwell or corridor can also be a problem.

Houses built or modified for people with MCS usually emphasize traditional and inert materials, such as fired bricks, tile, concrete, glass and steel (Baker-Laporte 2014; Evans 2019; Rea 2002). If the budget is large enough, then gorgeous houses can be built using more exotic materials (Tudhope 2018).

These types of materials are also more durable and less prone to mold growth. This limits the need for upkeep, which is also a problem for the resident.



A bedroom built for someone with severe MCS.

People are often more sensitive to mold and chemicals at night, so it may be sufficient to modify a bedroom as a sanctuary in order to get restful sleep. Such nocturnal sensitivity is also known for asthmatics, and has been reported as far back as the Roman age (Greenwood 2018).

Doing major construction or renovation is a large and costly task that is beyond many people's ability and financial means, especially since MCS often causes a drop in income as well (Soderholm 2011; Gibson 1996).

There is a large unmet need for healthy housing for people who cannot afford the cost of commercial projects. We are aware of just four projects built with money from governments or foundations to keep the rent low. They are located in Canada, Switzerland and the United States and all have long waiting lists.

In a 1996 survey, 305 people with MCS rated how environmentally safe their present home was:

Very safe	5%
Mostly safe	36%
Should be better	44%
Mostly unsafe	11%
Not safe	5%

Source: Gibson 1996.

There is no reason to believe these numbers are any different today. Too many people have to make do with marginally safe housing.

An alternative is to look for a healthier home to move to, but that is difficult to find and may not work out after all.

In one study, 13% of people with MCS had to change residence (Caress 2002). In two others, about half had to move residence (Miller 1995; Gibson 2003). Some had to move many times (McCormick 2001; EI wellspring 2009).

In extreme cases people have been forced to abandon their home and live in cars, vans, trailers, tents or on covered porches for some time (Gibson 1996; Hermann 2000; McCormick 2001; Evans 2010, 2019; Lipson 2001).

Some people move long distance for a better climate and less air pollution. There is no perfect place, though on the coast, in the desert and on high mountains are popular choices.

Financial impact

MCS often has a major impact on the person’s finances. There is no reliable cure, but lots of treatments offered by physicians and alternative practitioners. Most of them are not covered by health insurance. Many patients exhaust their savings in a desperate attempt at stopping the illness.

Building or modifying the home to create a non-toxic environment is also costly. Many cannot afford it.

Severe cases become unable to work and have to apply for disability. The process nearly always includes evaluations by one or two physicians hired by the insurer. These evaluations are often unpleasant and undignified (Evans 2010; Gibson 2016b). It is vital to have a sympathetic physician help with the medical documentation, but few physicians are willing to help (Gibson 2011a).

The process often takes a couple of years, during which the patient has to live without income and health insurance. Once granted, the payments can be so low they do not even cover the rent.

The loss of income and loss of savings can force people to become homeless (Gibson 1996; Hermann 2000; McCormick 2001).

Lifestyle impact

The impact on a person's lifestyle depends on the severity of the MCS illness. Most people are on the milder end of the spectrum and may just need to change some personal care products and laundry products, and perhaps avoid particularly strongly fragranced public restrooms.

For people on the severe end of the MCS spectrum, the illness can be completely life altering (McCormick 2001; Evans 2010; Gibson 1996, 2005; Katerndahl 2012; Driesen 2020; Soderholm 2011; Lipson 2001, 2004; Skovbjerg 2009a; Miller 1999).

These are the people the media focuses on, even though they are only about 3% of the total MCS population (Kreutzer 1999; Berg 2008).

Virtually every part of their daily lives has to be considered, such as all personal care and laundry products, cleaning products, brand of toilet paper, clothing materials, hobbies, food products, home maintenance etc. It is likely to be difficult to buy a car, or travel on public transportation (bus, train or airplane).

New purchases of clothing, bedding, furniture, electronics and much else must be carefully considered and then "detoxed" before use. New clothing and bedding needs to be washed many times before using, and synthetic materials avoided (especially polyester). Waterproofed outerwear can be especially difficult to detox.

A new computer or television may need to be turned on and run for months in a well-ventilated space, such as a garage. Some people put them in a ventilated box with a glass window.

Going to a store is often a problem because of the fume exposures (Kreutzer 1999; Lipson 2001; Larsson 2009).

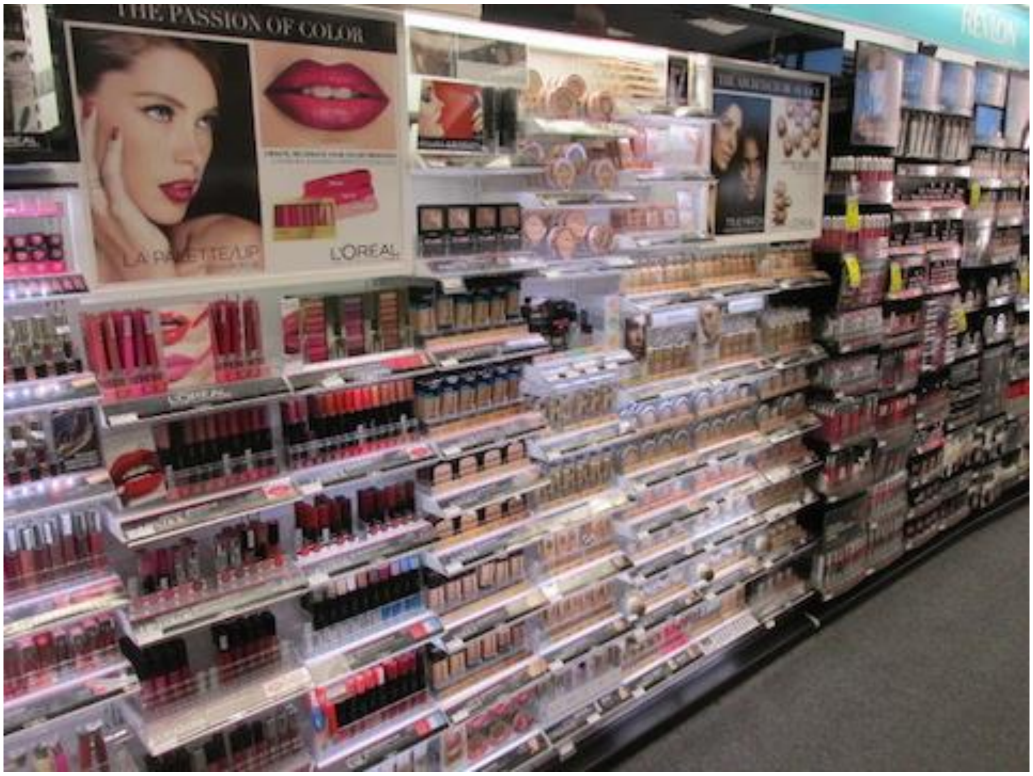
People cope in various ways, such as shopping at times when there are few people; use "profiling" to steer clear of people who may wear strong perfumes; limiting the time inside, or using a respirator. Some send a spouse or hire a shopper (Gibson 2005; Skovbjerg 2009a; Evans 2010, 2019; Soderholm, 2011).

Even wearing a respirator is not a true solution. They leak, and the chemical fumes can enter the body through the eyes (Millqvist 1999). Many refuse to wear a mask, due to the social awkwardness.

Visiting theaters, restaurants, cafes, concert halls and public transportation becomes very difficult. They may have to leave prematurely. Many simply give up on such places (Gibson 1996, 2011b; Skovbjerg 2009a; Larsson 2009; Soderholm 2011)

Going to a hairdresser becomes difficult or impossible because of the products used there (Soderholm 2011). Some people cope by using a small salon that doesn't do the most toxic hair treatments, and then be the first customer of the day, but even that may not be sufficient. A popular magazine featured a woman whose hair was cut outside while snow was falling (Sorgenfrei 2004): www.eiwellspring.org/stories/HerHaircutIsOutside.htm.

This is just a simple example of the daily difficulties living with severe MCS.



Other people's use of cosmetics and personal care products can be a major problem.

The impact on social life is often dramatic, since friends and family may be unwilling to change their personal care products to non-toxic versions. They can't just become non-toxic by not putting on their usual products the day of a visit, which is really hard to understand for someone who doesn't have the illness (Soderholm 2011; Miller 1999; Gibson 2006, 2011; Skovbjerg 2009a; McCormick 2001).

This writer has several times encountered people who sincerely believed they were absolutely fragrance free – and yet they were easily smelled even 15 feet (5 meters) away. It is a truly difficult problem.

People with severe MCS are often forced to make difficult decisions. If they attempt to get friends and family to accommodate their need for clean air, it is awkward and against the social protocol to "criticize" how a person smells.

The stigma makes some too embarrassed to disclose their illness to others (Lipson 2004; Gibson 2005; Larsson 2009). This dilemma is also documented for other illnesses that carry a stigma (Joachim 2000).

Many try to live with the painful symptoms, which may last for days, in return for a social life. But it is really hard.

A common situation is when a friend shows up, but is too stinky to invite inside. The friend may even feel proud she didn't put on her favorite perfume that day, but her clothes still reek of fabric softener. A very awkward situation with no socially acceptable solution.

Eventually these situations often result in broken friendships and even broken families (Gibson 2005, 2011b; Lipson 2004; Soderholm 2011).

Going out to meet new people for friendships and possible romance is virtually impossible. On top of that, MCS makes it very difficult to use the cosmetics, hair treatments, and fancy clothes that are often expected of women (Gibson 2005, 2006).

The end result is that many people with severe MCS end up living in forced social isolation (Gibson 2005; Skovbjerg 2009a; Soderholm 2011).

Some women choose not to have children because they fear they'll pass the disease on to their child, and their lack of access to medical facilities. This also increases the isolation (Gibson 1996).

Senior citizens with MCS are particularly affected. Family and friends have often become distant a long time ago because of the illness and are not available to help out. Home health care, assisted living, nursing homes and all sorts of medical care are all poorly prepared to accept and accommodate the needs of someone with MCS. Some people simply hope to die before they need these services (Gibson 2016a).

Communities

In response to the social isolation and lack of medical help, MCS communities have operated for many years. They offer the comfort of talking to other people who understand and respect the illness, and who may offer advice to newbies.

Some find community in social media. Some find other people with MCS to visit, since they are non-toxic as well. There are informal support groups in some cities, which sometimes host social gatherings (Lipson 2004).

Informal communities have sprung up around southwestern United States in places with good air quality so people can socialize and help each other (EI Wellspring 2020; Evans 2019; Dye 1983; Wallace 1990). One of them even inspired a novel (Sedgwick 2019). The picture on the front of this article is from the Dolan Springs community in Arizona. The cover of Part 1 shows people from the community in Snowflake, Arizona.

With the great diversity of the people who have MCS, there is also diversity in the communities. This includes people who both have MCS and are Jehovah's Witnesses, and people who are also lesbian.

Before social media, there were a lot of local social clubs for people with MCS. In 1986 there were at least 72 across the United States (HE 1986).

Mental health impact

People with MCS are constantly bombarded with chemical fumes from strangers, coworkers, friends and loved ones. It can happen any time with no warning.

Even though the attackers rarely intend to harm, they also rarely comprehend the impact and tend to ignore and downplay any complaints. Most refuse to stop the insults. The authorities, especially the medical profession, provide no help and may even add to the abuse. Defense against the onslaught is very difficult and often seen as socially unacceptable.

It is very much like living with an abusive spouse or parent. The abuser never takes responsibility, is incensed by any complaint, and often blames the victim.

At the same time, those with severe MCS are also faced with job loss, loss of savings, loss of family, and maybe even loss of their home.

It is no wonder people with MCS are more prone to depression and anxiety than the general population (Park 2017). And also no wonder that there is more such problems among those who seek medical help for MCS, i.e. the more severe cases (Black 1990; Bornschein 2002).

This effect is also seen in people who do not have MCS, but live with domestic violence (Ludemir 2008; Adkins 2010; Alejo 2014). And in people facing other life-altering illnesses, such as terminal cancer (Niedzwiedz 2019; Walker 2013).

Forced social isolation often has a psychological impact, regardless of the reason for the isolation. Even people who are quarantined due to infectious disease are often affected, even when they know it is of short duration (Brooks 2020).

As a result of the hardships and the imposed social isolation, people with MCS score lower on "life satisfaction" surveys than most other groups of disabled people (Gibson 2016b).

The workplace

The workplace can be very challenging for someone with MCS. Industrial workshops can contain many types of solvents and other chemicals. Offices often have carpets, partitions, furniture, and copy machines.

Computers and other electronics offgas chemicals for many months that can impact staff productivity (Bako-Biro 2004; Carlsson 2000).

In some countries businesses are regularly sprayed with pesticides to keep out insects.

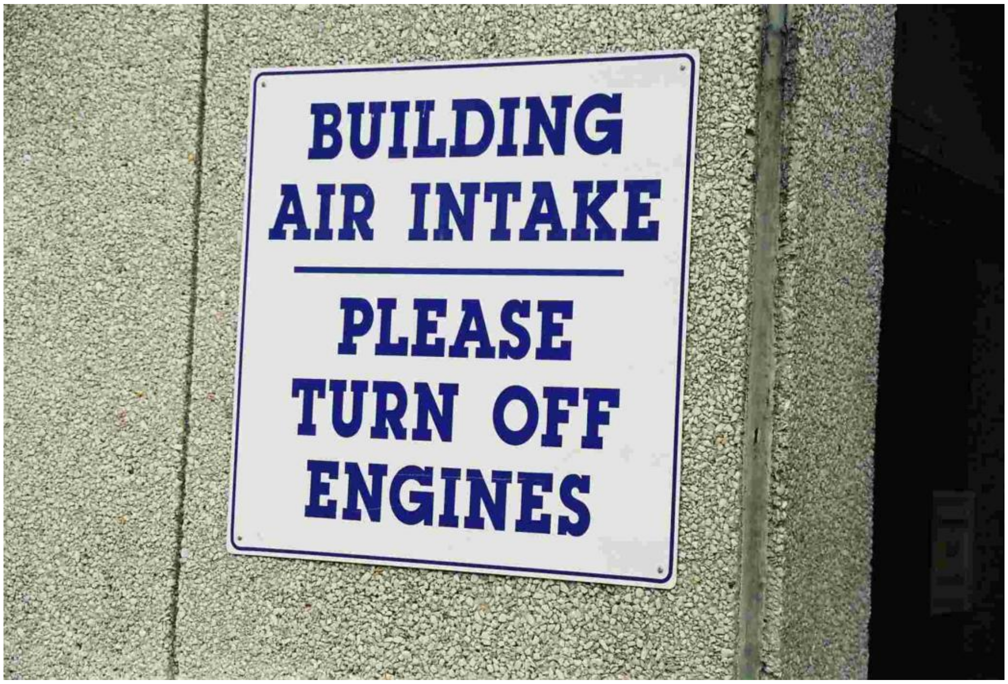
Various renovations or redecorations may take place every few years to give the place a "fresh" look that shows customers this is a successful company.

The rest rooms are likely to be fragranced.

Then there are the co-workers and their use of fragrances, fabric softener and other chemicals. Some may even bring in so-called air-fresheners for their desks (Larsson 2009). Even when smokers go outside to smoke, they emanate toxic gasses from their clothes and breath for hours afterwards (Sheu 2020).

Some co-workers intentionally harass people with MCS (Lipson 2004; EIwellspring 2019b; McCormick 2001:Wilke).

Ventilation is often inadequate even when following all guidelines. Guidelines are always a compromise with the energy cost of heating and cooling the incoming fresh air.



The air intake to many office buildings does not provide clean air because of poor location at street level.

The ventilation standards for the United States are designed for healthy people, with indoor air that needs to just satisfy 80% of occupants (ASHRAE 2004; EPA 1988). That means it is "acceptable" when 20% of a building's occupants find the air quality objectionable.

US federal workplace standards (OSHA/NIOSH) are also not protective of sensitive people (ASHRAE 2004).

Increasing the ventilation and limiting indoor air pollution can improve the productivity and creativity of office workers, even those who are not chemically sensitive (Allen 2016).

The United States and many other countries have laws that require employers to make "reasonable" accommodations for disabled workers. But in praxis, many employers refuse – or it is not realistic.

In the United States, the Equal Employment Opportunity Commission (EEOC) handles complaints about discrimination. In a study of 1183 MCS-related complaints in the years 1992 to 2003, they found the most common complaint was failure to accommodate their disability. But in only 16% of the cases did the EEOC support the employee with MCS (Vierstra 2007).

Many people with severe MCS are forced to change jobs, become under-employed or lose their jobs entirely (Miller 1995; Kreutzer 1999; Caress 2003, 2004; Gibson 2005; Berg 2008; Evans 2010; Soderholm 2011; Loria-Kohen 2017; Park 2017).

Some end up self-employed and working at home. Unless they have professional skills it is often poorly paid and unsteady work, as the competition is fierce, including from people with other disabilities.

About twenty percent of the patients seen by Dr. William Rea go on disability. He sees the most severe cases, so the number is less for the overall MCS population (Ashford 1998: ch 6).

The backlash

When MCS turned out to be more than just an oddity and revealed itself to be a threat to powerful special interests, there was a major backlash with effects still strongly felt today.

In the 1960's there was a fundamental disagreement among the allergists in the United States about how to treat allergies and what MCS was. In 1965 it came to a complete break and a group of allergists formed a new medical society, which today is named American Academy of Environmental Medicine (AAEM) (Randolph 1990; Spetz 1966).

This resulted in a nasty turf war. The field of medicine (at least in the United States) attracts people with powerful egos, and they took a dim view of these upstarts with their heretical teachings that threatened much dogma. A contemporary source stated:

> *[It's] an ever widening and hostile debate in which the patient is held hostage and virtually all clinicians are rendered impotent because of widely known intraprofessional disagreements* (Cullen 1987: Conclusion).

See also (Ashford 1998: ch 2 & 9; Brodsky 1987; Miller 1994).

Conventional doctors' practices were based on doling out drugs. Many MCS patients didn't tolerate the drugs (see earlier) and the environmental physicians also considered drugs mostly symptom treatment and not actually addressing the illness. This did not go over well. Then when the allergists started to lose members who deserted to the new teachings – and many patients also defected – that further incensed the old guard (Randolph 1990; Hileman 1991).

Another bone of contention was that the upstarts experimented with a great variety of treatments, and what seemed to work became established practice. They were focused on helping their patients as best they could (Ashford 1998).

There was no funding available for doing academic research to prove these treatments really worked and wasn't just a placebo. This use of unproven treatments hurt the whole field and gave more ammunition to the detractors (Meggs 2017b; Miller 1994).

There was a lot of sniping, such as:

> *The variety of treatments seemed to be limited only by the imagination and resourcefulness of the clinician* (Black 1990).

See also: (AAA 1981; CMA 1986; Brodsky 1983, 1989; Black 1990, 1996; Molot 2014)

There were, of course, also more sober physicians who raised genuine and fact-based critique of some of the new methods and thinking (Jewett 1990; Kipen 2002).

The critics can be accused of hypocrisy, since allergists themselves used various treatments for decades before they were understood and validated by science (Ashford 1998: ch 10).

The opponents of MCS pointed out that there was not enough research to prove MCS even existed. But when the California legislature approved funding for such research, the opponents convinced the governor to veto the bill (Randegger 1985).

Since MCS can cause symptoms that vary from patient to patient, some opponents take that to indicate it is all psychosomatic. However, other illnesses have varied symptoms. Radium poisoning can cause tooth loss, joint pains and anemia (Moore 2017). Cigarettes can cause many diverse effects, such as lung cancer, infertility, low birth weight, bone loss, heart attacks, and strokes (CDC 2021). No less than 203 symptoms are attribute to long-covid (Davis 2021).

Some of the opponents even claimed that the physicians trying to help the sick people made it worse by believing their patients instead of referring them to a psychiatrist (Terr 1986, 1993; Black 1996)

Physicians became afraid of even suggesting to their patients that they avoid certain chemicals, as they feared being disciplined by their local medical board.

Some physicians had to fight costly legal battles to keep their licenses (Hileman 1991; Nelson 1994b; Lipson 2004; Meggs 2017b).

More recent hostility was on display when professor Pam Gibson wanted to distribute a survey to physicians attending an annual medical conference. The request was denied based on the questions, which gauged the physicians' attitudes towards MCS (Gibson 2011).

The situation was much like the story about the physician Ignaz Semmelweis, who in the 1840s Austria discovered that if physicians washed their hands between seeing patients, it sharply reduced deaths from infectious diseases. He was able to scientifically document this effect, but he could not explain why, since bacteria had not yet been discovered. Dr. Semmelweis was driven out of town by his incensed colleagues (Wikipedia).

Sufferers of other ill-defined illnesses, such as Gulf War Syndrome, chronic fatigue syndrome, fibromyalgia and endometriosis have seen similar hostility (Zavestoski 2004; Gibson 2005; Ware 1992; Ballweg 1995).

The mental health professions have right from the start insisted that MCS is simply a mental disorder (Brodsky 1983, 1989; Black 1990, 1996). They do not at all consider that the depression and anxiety they find in some of the sick people are actually caused by the severe trauma of getting sick and facing a very hostile world (as described throughout this document).

A study at Johns Hopkins University demonstrated that MCS patients who are know to have no mental health problems at all will still be given a psychiatric diagnosis if they present with symptoms of MCS (Davidoff 2000).

Some psychiatrists even postulate that all the illnesses that are not yet understood are really just one and the same sort of psychiatric illness they call "functional somatic syndrome" (Wessely 1999).

This conflict has hurt the MCS patients. As Ashford and Miller wrote in their seminal book (1998: ch 2):

> *Many are intelligent individuals who are angry at traditional medical practitioners for their unwillingness to study and understand this illness. As individuals with chemical sensitivities are caught up in the escalating debate among medical practitioners, they find if more and more difficult to obtain unbiased, useful information regarding their condition.*

The big losers in all this squabbling and grandstanding are the patients, as we shall see in the next two sections.

A second front against MCS appeared around 1990. More people were getting sick with MCS, and they were featured in media stories that pointed fingers at carpets and other toxic materials (a few examples: Dye 1983; Toufexis 1988; Belkin 1990). There were also several lawsuits from workers who got sick on the job. A group of employees sued the aircraft manufacturer Boeing in Seattle (Nelson 1994a; Sparks 1990).

This made various industry associations take notice. An internal memo to members of the Chemical Manufacturer's Association, stated that if MCS became accepted it would cause "enormous cost" to their members (Credon 1990). The document spelled out various ways to oppose and discredit MCS, including lobbying and providing assistance to the physicians who were willing to speak out against MCS.

A few months later the industry journal *Chemical & Engineering News* published a theme issue about MCS. It hammered home the threat with statements such as "Clearly, the economic stakes in this issue are very high..." (Hileman 1991).

Other industries had already had great success fighting similar threats, such as against tobacco, asbestos and several chemicals (McGarity 2008; Michaels 2008).

The tobacco industry claimed that when people with asthma or MCS were sickened by other people’s cigarettes, it was simply a psychological issue (Witorsch 1992a). Of course, it was done without disclosing the tobacco industry was involved (Witorsch 1992b).

When the message is not welcome, attacking the messenger works quite well.

Such methods were employed extensively against people with MCS, including claims that MCS was just "all in their head," creating an innocently named "research" center that did no research but spewed propaganda, sponsored newspaper articles, attempts at changing the name of MCS and much else (McCampbell 2001; EI Wellspring 2022; Donnay 1997; Abrams 1996; Ashford 1998: ch. 9; Lipson 2004; Nelson 1994a).

A series of seven TV programs dismissive of MCS were aired on American Broadcasting Corporation from 1989 to 1997. They had titles such as "Big fears, little risks," "Allergic to the world" and "Are we scaring ourselves to death" (Lipson 2004; ABC TV note)

These efforts were highly successful. The popular media brought fewer stories about MCS, and they became much less sympathetic. MCS advocates were ignored by government agencies that used to be willing to talk to them (Molloy 2019). Funding for MCS research dried up (Meggs 2017b). MCS is almost as controversial today as it was in the 1990s. The human cost has been enormous.

The human cost of continued controversy

As long as MCS is still falsely believed to be a psychiatric illness – i.e. illegitimate – very little progress is possible for treatments, accommodations and human dignity.

The MCS patient can be pressured by family and physicians to undergo inappropriate psychiatric treatments. These can actually be harmful, both the drugs and if the person is told to keep exposing herself to toxic chemicals (Gibson 2003).

Physicians who believe a patient is imagining any illness tend to ignore symptoms of other illnesses, resulting in lack of care (Groopman 2008; McColl 2010). They may even provide the wrong kind of care. As psychiatrist van der Kolk wrote (2014):

> *When there is no relationship between diagnosis and cure, a mislabeled patient is bound to be a mistreated patient. You would not want to have your appendix removed when you are suffering from a kidney stone, and you would not want have somebody labeled as "oppositional" when, in fact, his behavior is rooted in an attempt to protect himself against real danger.*

Medical misdiagnosis and mistakes are a major problem that receives little attention. Nearly 100,000 Americans die every year because of it, yet no statistics are kept and it doesn't show on the death certificates (Makary 2016; Sutcliffe 2019; Lazarou 1998).

Physicians and staff in clinics, hospitals and nursing homes may refuse to accommodate the sick people, and even ridicule them (See the Health Care section earlier).

Bosses and co-workers can feel justified denying accommodations, and even actively harass the disabled person (EI Wellspring 2019b).

Family members can also feel they have a license to sabotage the sick person. The result is often a broken family at a time when the sick person needs help and sympathy the most (Gibson 1996).

Bullies on social media feel justified ridiculing people with MCS (EI Wellspring 2018).

The World Health Organization continues to refuse to issue a diagnostic code for MCS, despite scientific support (Brussels Declaration 2015; Belpomme 2020). This makes it "acceptable" for insurance companies to refuse paying medical bills and disability for those who can no longer work (Dumit 2006).

Many people disabled by MCS face the choice of accepting an incorrect psychiatric diagnosis, or not receiving any insurance coverage. A psychiatric diagnosis carries a major stigma, and often has much poorer insurance coverage than non-psychiatric illness (Dumit 2006).

A supportive physician is essential for receiving disability payments, but many physicians refuse to help, while some even actively sabotage the process (Lipson 2004; Gibson 2011).

Unable to work, sick, and financially destitute, with little or no support from family or social services, some patients become homeless. It can be a fast decline from a middle-class life to the bottom (Gibson 2005).

Depression and other mental health problems often follow as a result of the ordeal – and may seemingly "prove" that it was all mental to start with. Suicide may be the final outcome (Dye 1983; Evans 2010; Worth 1994).

People with other controversial diseases have similar experiences (Cara 2017; Haas 2018; Dumit 2006).

Lack of research funding

Many fundamental questions about MCS are unanswered, such as the biological mechanism, a clear definition, and objective diagnostic tests. And yet, there is barely any such research happening, because there is no funding available.

A detailed search of the PubMed database found only 320 articles specific to MCS. This compares with 7453 articles about chronic fatigue syndrome and 9846 about fibromyalgia (Hu 2018). Similar results were found by an earlier study (Zavestoski 2004).

Funding is very hard to get until a new field of study has "proven" itself, especially if it is stigmatized with a controversy. And without funding a field cannot "prove" itself to be legitimate. It's a vicious cycle. Instead, funding tends to flow to well-established fields. As *Scientific American* wrote: "Review panels, even when they are made up of excellent scientists, are allergic to risky ideas ... It must be mainstream ..." (Ioannidis 2018).

Another scientist, in a field that also threatens corporate interests, stated:

> *Funds are given to those who stay well within the confines of their field, not to those who push the envelope.* (Davis 2002: ch 3).

MCS primarily affects women. It is well documented that "women's diseases" tend to be minimized, psychologized and starved of funding for research (Lipson 2004; Sole-Smith 2019; Ballweg 1995; Ware 1992).

MCS has the additional problem that special interests much prefer that it is *not* studied but remains controversial (see previous section). This may explain why MCS receives even less funding than chronic fatigue syndrome and fibromyalgia (Hu 2018), which are both controversial "women's diseases," but not a threat to special interests.

One scientist reports the frustrating run-around he got when applying for research grants, including being told that research could not be funded since "everybody knows that MCS is psychological" (Meggs 2017b).

All MCS research has been done on shoestring budgets. That is especially obvious when looking at the many challenge studies, which used primitive facilities, were generally poorly done, and unsurprisingly gave contradictory results. In stark contrast is a well-funded and well-designed indoor air quality challenge study by Harvard University researchers (Allen 2016). It used healthy volunteers. Such a study has never been done on MCS patients.

But when MCS sufferer Marilyn Brachman Hoffman bequeathed Harvard University five million dollars to do MCS research and education, they didn’t do any MCS research at all and the money mysteriously disappeared (EI Wellspring 2022).

Another fundamental problem is that much medical research focuses on treatments, while few focus on prevention of illness. This bias reflects the conflict of interest that treatments are wildly profitable, while prevention means loss of business. A disease that makes people not tolerate drugs does not interest drug companies and they have a strong influence on public health research.

The U.S. National Institutes of Health spends $39 billion every year on medical research (NIH 2019). Little or none of it goes to MCS research, despite MCS being much more common than some well-funded illnesses (Hu 2018). In the scientific articles we read through to write this article, few specified their funding. The few that did tended to list foundations or general funds from a university.

What little funding is available also appears to have a bias. In recent years there were many more studies on the "emotional problems" associated with MCS than studies looking at some of the fundamental questions.

Reading through all the reference materials for this article, it was shocking how many of the studies were written by psychologists or psychiatrists. There is a great need of other perspectives than psychiatry. If you have cancer you need research by cancer specialists.

Celebrity patients

In America, the acceptance of a disease is helped tremendously if a celebrity steps forward, as happened with Rock Hudson, Betty Ford, Christopher Reeves and others. So far some celebrities have been spotted at an MCS clinic in Dallas and some rumours, but nobody has stepped forward.

Activism

People with MCS are ridiculed by popular media (Laneri 2020) and ignored by agencies that can fund medical research and set standards for access to medical facilities and other public places. Other groups have been in a similar situation in the past.

In the 1980s gays were portrayed as weird people on television and there was little funding for AIDS research which was seen as a gay-only disease. Activists worked on these issues in various ways, including large demonstrations in front of the National Institutes of Health and convincing Hollywood to treat them fairly (Faderman 2015).

Advocates were also a major factor in getting research funding for Alzheimer's disease in the 1980s (Nuland 1993).

In 1990 a group of wheelchair users crawled up the hundred steps to the U.S. Capitol in Washington, DC, to shame lawmakers into passing the Americans with Disabilities Act, so wheelchair ramps could be built (Welch 1990).

In the 1990s, soldiers who got sick in the Gulf War had to get organized too, to force the U.S. Veterans Association medical system to take them seriously and not just write them all off as psychiatric cases (Zavestoski 2004).

MCS activists have worked in the United States since the early 1980s (Sledd 2010; McCormick 2001). Some results are that airlines no longer harass passengers with MCS, some hospitals and work places have gone fragrance-free, and several state governors have issued proclamations supporting people with MCS. Two housing projects have been built for low-income people with MCS. But the unmet needs are enormous and there is much work left to be done, such as ensuring access to health care facilities, government offices, etc (Sledd 2010).

There has been a multi-decade effort to get the U.S. Access Board to help. It's the federal agency tasked with ensuring disabled people can access public buildings, among other places. Despite the ongoing efforts, including several activists showing up at their 2018 public hearing in Phoenix (Access Board 2018), they have only provided a couple of small tokens and never actually taken the issue seriously (Molloy 2019; Lamielle 2020).

Some of the European patient organizations have worked hard to get the World Health Organization in Switzerland to recognize MCS, and issue a diagnostic code so MCS will show up in the statistics. But the efforts have been politely stonewalled.

The main needs are:

- To be respected as human beings and not be falsely portrayed as crazy people.
- Housing that is safe and affordable for people on a low disability income.
- Funding for research that is actually helpful and not just shoring up the misguided "psych" model.
- Access to health care facilities, such as clinics, hospitals, and nursing homes.

The basic problem is that it is hard for sick people to go to the halls of power, where they'll get even sicker. It is impossible to make major demonstrations that will get the attention of the press and shame the officials enough to actually do something. And when there is some headway, the chemical industry sends in their lobbyists (McCampbell 2001; Hamilton 1994).

Another fundamental problem is that making medical clinics and other places safe is not simple. It also infringes on people's perceived right to reek of fragrances, just as smokers used to think they had the right to smoke anywhere they pleased – even inside a hospital.

It will be a slow and bumpy ride to get even existing laws enforced. Following the enactment of the Americans with Disabilities Act in 1990 there was a lot of resistance to building wheelchair ramps, parking spaces and bathrooms, and against people with disabilities that were not clearly visible (NYT 1989; Johnson 2003).

It seems that the MCS community has overlapping interests with several other disability groups, such as those with autism, chronic fatigue, electrical sensitivity, asthma and fibromyalgia. It would make sense to set up dialogs and possibly cooperate on projects.

Attempts to seek allies in the general disability community have not been successful. Other groups apparently fear to lose what little prestige they have by associating with an even less "accepted" group (Sledd 2010). This is on display in the documentary film *The Sensitives* when an MCS activist travels to a disability activist meeting under great difficulty, and can't even get a footnote added to some policy document.

In popular media

Fictional characters with MCS appeared for the first time briefly in 1992 in the TV shows *Northern Exposure* and *L.A. Law.*

The 1995 film *Safe* was about a woman with MCS, though the film was really a commentary on the AIDS crisis, suburban angst and questionable New Age health advice.

The 2018 Netflix series *Afflicted* featured two people with MCS.

In all of the above, the MCS patients are portrayed more or less as weird.

For a more positive portrayal, there are the films *Homesick* (2013) and *The Sensitives* (2017). Both are documentaries made by individuals with a deeper understanding of the illness. But neither of them has reached many viewers.

Myths and misconceptions

There are many myths and misunderstandings around MCS. Social media and popular media pass around myths and some become accepted fact. This is similar to many other controversial subjects, such as politics.

The myths we see come both from outsiders, who voice their opinions about people with MCS, and from patients who grapple with how to cope with the illness, with just social media to help them.

In 2016 the popular news outlet *The Guardian* posted a video on YouTube about people with MCS living in Snowflake, Arizona. An analysis of seven hundred social-media comments clearly demonstrated how outsiders showed strong bias and even made up things they claimed to see, but which wasn't in the video at all (EI Wellspring 2018). The video stated the three people with MCS were "self-diagnosed," even though all were diagnosed by a physician. Such slurs undermine the legitimacy of MCS.

Many of the comments tried to "prove" that the people they saw were making things up by pointing out what appeared to be "inconsistencies," but actually were not. Some of these commenters even built on each other, so a stinky new book became older and older as "proof" that the fumes could not be a problem.

Recommended books

12,000 canaries can't be wrong, John Molot, Toronto: ECW Press, 2014.

Amputated Lives: coping with chemical sensitivity, Alison Johnson, Cumberland Press, 2008.

An alternative approach to allergies, Theron Randolph and Ralph Moss, New York: Harper and Row, 1990.

Chemical and electrical hypersensitivity: A sufferer's memoir, Jerry Evans, Jefferson North Carolina: McFarland, 2010.

Living with multiple chemical sensitivity, Gail McCormick, Jefferson, NC: McFarland, 2001.

Multiple chemical sensitivity: A survival guide, Pamela Reed Gibson, Churchville, VA: Earthrive, 2006.

The canaries, Thilde Jensen, LENA Publications, 2013.

The case against fragrance, Kate Grenville, Melbourne, Australia: Text Publishing, 2017.

The dispossessed: living with multiple chemical sensitivities, Rhonda Zwillinger, The Dispossessed Project, 1999.

The healthy house quest, Jerry Evans, Snowflake, AZ: Turquoise Rose Publishing, 2019.

Recommended readings for physicians

Multiple chemical sensitivity: review of the state of the art in epidemiology, diagnosis, and future perspectives, Sabrina Rossi and Alessio Pitidis, *Journal of Occupational and Environmental Medicine* (open access) 60, 138-146, February 2018.

Multiple chemical sensitivity: low levels and high stakes (second edition), Nicholas Ashford and Claudia Miller, New York: Van Nostrand Reinhold, 1998. Out of print, but obtainable through libraries and free download.

Italian consensus on multiple chemical sensitivity, Italian workgroup on MCS, 2019.

The medical perspective on environmental sensitivities, Margaret Sears, Canadian Human Rights Commission, 2007. (Available for free download in both English and French.)

Recommended films

Homesick: living with multiple chemical sensitivities, Susan Abod (director), USA: Dual Power Productions, 2013.

Multiple chemical sensitivity: a life-altering condition, Alison Johnson (director), USA: Johnson/Startzman Film, 2013.

The Sensitives, Drew Xanthopoulos (director), USA: Normie Productions, 2017.

More information

Part 1 of this particle, as well as articles about living with MCS, the history and much else are available through www.eiwellspring.org/intromenu.html.

References

The references to this document are available at www.eiwellspring.org/health/IntroductionToMCSreference.htm.

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