

Living with MCS in the 1980s



In the 1980s the MCS community got organized in the United States. They had magazines, support groups, rural hideouts and small businesses providing special goods.

Before it was called MCS

The term “multiple chemical sensitivity” (MCS) was first coined in 1987 by Mark Cullen at Yale University. It took some years to catch on. Meanwhile, people mostly referred to the disease as “environmental illness,” (EI), “ecological illness,” or some more vague references to being “sensitive.” Some used the term “allergy” as it had not yet been shown that MCS does not fit the medical definition for allergy (today’s media still have not figured it out).

Not easy in the 1980s

In the 1980s MCS was a disease nobody had heard about, though local papers on the West Coast of the United States occasionally published a sympathetic human interest story.

Smokers considered it their fundamental right to smoke anywhere they pleased, including offices, airplanes, restaurants and even hospitals.

New cars came with catalytic converters to reduce their exhaust pollution, but there were a lot of older cars without them, and diesel engines had no such devices yet.

There were no laws about providing access to public buildings and workplaces for people with disabilities.

Stores did not stock natural and organic foods.

What did people do to survive?

Medical politics

MCS was largely unknown by physicians in the 1980s. A few pioneering doctors called themselves “clinical ecologists” and tried to help their patients as best they could. With no money for medical research they had to try ideas on their patients. What seemed to help some then became more established, but the field suffered from a lack of academic support.

What motivated many of these pioneering physicians was often that they had MCS themselves, or a close family member did. They knew how devastating MCS was, and that it wasn't something people made up.

Medical politics was already a big issue, centered around a few critics in California, such as Abba Terr and Carroll Brodsky. John Selner and Herman Staudenmayer in Colorado were also active critics.

The California Medical Association was compelled to issue dismissive statements about clinical ecology in 1981 and 1986.

The most outspoken anti-MCS physician was the allergist Abba Terr whom the *Pacific Sun* in 1983 called “a veritable one-man crusade against the concepts of environmental illness and clinical ecology.” He had a thriving business helping companies sued by people who got MCS on the job, and insurance companies faced with MCS disability claims.

Support groups

There was no social media in those days. People banded together in support groups for socializing and learning from each other. The national organization

HEAL (Human Ecology Action League) started in 1977 and had 32 local chapters in 1985, with some of them having local sub-groups too. The HEAL chapter in Michigan had no less than twelve local affiliates.

In California there was a separate organization named Environmental Health Association (EHA), which had seven local chapters around the state.

Then there were many small independent organizations around the country. A 1986 tally shows a total of 72 support groups in 24 states (HE 29, 32).

The HEAL organization published the magazine *The Human Ecologist*, while the Environmental Health Association published *The Reactor*. Many local groups also put out newsletters.

Despite the “action” in its name, HEAL did not do advocacy work. EHA on the other hand did, including, getting the Marin General Hospital to go less toxic in 1988.

A benefit of the groups was they held meetings and picnics where people with MCS could have a social life without having to constantly dodge smokers and users of perfume. Here their illness was not constantly questioned.

MCS in the workplace

Surprisingly, there were no discussions in the newsletters on how to hold on to a job when suffering from MCS. Perhaps it simply was not possible.

The Americans with Disabilities Act that mandated employers provide “reasonable accommodation” of disabled people was first enacted in 1990. It replaced the nearly worthless Rehabilitation Act from 1973.

Workers routinely smoked at their desks. Carpets were notoriously toxic. Following the energy crisis in the 1970s, buildings had their windows nailed shut and ventilation systems set to use mostly recycled air.

Computer terminals were rolled out at large companies. These bulky screens gave off a lot of heat (typically around 100 watts) which evaporated plastic fumes and flame retardants right in the face of the user.

Moving away

People with severe MCS started moving away from the polluted cities to rural areas such as the Texas Hill Country around Wimberley, and to West Texas

around Fort Davis. Further west people moved to places like Mt. Shasta and Potrero in California, and to rural Arizona.



Newspaper articles about the MCS communities in Wimberley and Fort Davis, Texas.

There were several attempts at starting communities that didn't succeed. One was Ecology Ranch which was started by Joe Chancerelle somewhere in "North Central Arizona." Another was Scott's Mountain in the Texas Hill Country, which got suggestions from NASA in Houston on what non-toxic materials to use (HE Fall 1984).

A realtor in Prescott, Arizona, advertised they were in a small mountain town with "cool clean air" and could custom build an EI home or find a good lot (HE 42).

The 1980 book *Sunnyhill* by Bruce and Barbara Small tells the story of a family of three who all have MCS. In 1977 they fled polluted Toronto and built themselves a house in the countryside. The clean air and organic food they grew themselves made a tremendous difference.

Figuring it out

People figured out how to make their lives tolerable and shared the information in the newsletters and at support group meetings.

A woman in Richardson, Texas, described how to make a non-toxic bed by getting a metal bed spring (i.e. a mattress without any stuffing) and then place five quilted mattress pads on top. The pads can be washed until they are inert (HE 28).

Housing was an ongoing issue throughout the decade, in both feature articles and small notices. There was even an article about a small office building in Atlanta that was built safe from the ground up by the owner who had MCS. The office suites were used by the owner herself and also rented out to other small businesses (HE 31).

A pioneer of healthy housing, Mary Oetzel of Austin, Texas, provided advice in several issues. She discussed sealing walls with aluminum foil and sealing concrete with sodium silicate (“water glass”). She also announced that window manufacturers stopped using the toxic pentachlorophenol on wood-framed windows in 1986 (HE 28, 30, 34).

Non-toxic houses were advertised for sale, touting their special features, such as walls sealed with decorative aluminum wallpaper (HE 30).

Many laundry detergents already included fragrances, but they were mild compared to what became the norm a decade later. The manufacturers didn’t disclose what was in their products, but a physician was able to find out what was in Arm & Hammer’s detergent. A major ingredient was baking soda (sodium bicarbonate), which was why this product had special interest. But it also had several nasties, including perfume. He also reported that some borax was perfumed (HE 22).

Activism

People were mostly focused on getting along with the toxic majority, and not stirring up trouble. But in a few places activists tried to improve the situation, especially in Chicago and California.

The most notable accomplishment was getting an MCS bill through both chambers of the California legislature in 1984. But last-minute lobbying convinced the governor to veto it. A second attempt in 1985 didn’t go far. These bills would have funded MCS research and a public health information campaign (HE 29).

We hear about the battle for the first ordinance requiring pesticide applicators to set up warning signs after they've sprayed lawns or buildings with public access. One of the activists got elected to the Wauconda city council and the ordinance passed unanimously, despite the efforts of the pesticide industry, which then sued the town (HE 22, 30, 31).

Living with MCS

The magazines did not have many stories about what people had to deal with, presumably since all readers knew that from their own lives. But there were some.

In the spring 1983 issue of *The Human Ecologist* was a story about hunting for a new car. It was a very toxic experience between the salespeople's cigarettes, the fumes of new cars, and used cars sprayed with "new car smell" fragrance. The little dangling "air fresheners" existed already then too.

A large article discusses the stigma society bestows upon people with MCS, since they are so "deviant" from what is expected. It brings a lot of good quotes from people living with MCS (HE 22).

The article suggested that people with MCS:

"fit in" with what's considered OK or necessary when you can, so you don't stand out.

And suggests having a "public" front to appear "normal," just as other people with invisible disabilities do.

One of the biggest problems is that I don't do well in public places ... any place where there's a lot of people. I get depressed in four or five minutes, burst into tears, get weak, and pass out (HE 22).

[O]ne of the things that ... is most annoying is the constant need to explain why this or why that, and often explain it to unbelieving ears.

Some people internalize the stigma themselves:

I sometimes can't think why my boyfriend can like me when he could have some other girl who wouldn't have headaches.

Finding a friendly doctor was difficult, but very important:

The most important treatment that Dr. X gave me was that he believed in me and recognized me as a person of worth.

Another patient concurred:

It seemed no matter how weird I thought some of my problems were, he wasn't surprised, but rather said they were possible and often typical.

One doctor advises:

It would be foolish to think you can eat artificial dyes and flavors and expose yourself to all kinds of toxic acids and what not in water and foods, and not pay a price for it (HE 22).

In a 1987 article about dealing with children's environmental illnesses, we hear the story of a child who is wildly reactive to red food dye. When he was four years old, someone offered him a strawberry. He made Mom proud by asking "Did it grow red or did they make it that way?" (HE 35)

Smoking

Tobacco smoke was a big issue in the 1980s. Smokers generally considered it their basic right to smoke when and where they pleased. That included restaurants, restrooms, airplanes, trains, hospitals, elevators and workplaces. The problems that caused to people with MCS was mentioned in several issues of *The Human Ecologist*.

One student in law school was able to convince some of his fellow students to not smoke around him but "those few civil libertarians who thought only of themselves puffed smoke in his face to test him." (HE 22)

Smoking was allowed on all airplane flights, so a woman in Chicago who wanted to go to California looked into traveling by train. Amtrak could take her there in two days and they told her they designated one out of every four train cars for the smokers. It turned out people smoked everywhere, and the train staff refused to help. She had to wear a mask the whole trip, except when in the dining car, which mercifully had a real non-smoking section. When she complained to Amtrak management, she got no sympathy (HE 27).



But change was afoot. In the latter part of the 1980s, more and more restaurants were experimenting with non-smoking sections and found they were popular.

The big hotel chains were rolling out non-smoking rooms and reported they were popular. A hotel manager said those rooms sold out first. The manager of a new totally smoke-free motel in Dallas quipped that "It's great to go into a room and lay your head in a pillow and not have it smell like an ashtray" (HE 30).

Some cities and towns started restricting smoking in public places. Early pioneers were San Francisco and Palo Alto in California, and Fort Collins in Colorado. Their ordinances were enacted despite the nefarious Tobacco Institute spending heavily to defeat them with themes such as "the government shouldn't tell people what to do" (HE 23/24, 27).

It took until the end of the 1990s before smoking was banned in most indoor places in the United States, though some states were still lagging.

Fragrances

Fragrances and deodorizers were problems in the 1980s, but secondary to tobacco smoke. An article about the tobacco menace and how restrictions are slowly being enacted also asks "how about perfume?" (HE 23/24). We are still waiting...

The use of fragrances in all sorts of consumer products exploded during the 1990s.

MCS clinics

The decade was the golden age of the environmental control unit. Sometimes called an ECU or “EI unit,” they were specialized hospital wards where severe MCS patients were kept in a rigidly controlled environment for typically three weeks. By removing as many triggers as possible, most patients felt much better. They were then gradually tested with various foods and inhalants, to see which they reacted to.

Operating an ECU was very expensive. All meals were organic and cooked for each individual patient. Drinking waters came in glass bottles from the most pristine sources. The building materials and methods were to exacting specifications.

By the end of the decade insurers balked at the cost, forcing most of the ECUs to close down (Randolph, 1990; Temple, 1980).

Businesses catering to the MCS community

There were several small businesses that provided foods and equipment to people with MCS. Their ads can be seen throughout the magazines.

Reading boxes were available from the Safe Haven company in Jacamba, California. They sold both portable and vacuum versions (HE 30 p. 28).

Several companies produced high quality air filters, including E.L. Faust and Allermed, as well as less popular brands such as Air Conditioning Engineers. Water filters were also available in several brands, including the premium Seagull line made with stainless steel and no plastic.

There were companies making ceramic electric heaters that didn't offgas chemicals and were easy to clean to avoid fried dust.

If you needed a more tolerable paint, there were a few brands available of “low biocide/low fungicide” paints, though the offerings were sparse and still dicey. People who could afford it used walls of porcelainized steel plates.

For a generation of people with MCS, Granny's was the laundry detergent of choice. It was cheap, effective and odor-free.

A number of vendors provided organic cotton bedding, including Janice Corporation in New Jersey and several others.

Some mail-order companies offered a wide variety of MCS-products, such as from Jim Nigra and The Living Source.

Several small MCS businesses sprung up around Dr. William Rea's Environmental Health Center in Dallas. They sold organic cotton, air cleaners, porcelain travel trailers and more. There was a store called The Living Source in Waco and in Dallas a store called The Glass Bubble.

A company in Dallas called Basic Concepts built MCS travel trailers. Their 20-foot (7 meter) model cost \$28,500 in 1989. It had interior walls of 16-gauge steel panels covered with porcelain, a plastic-free bathroom and copper water pipes.

BCi **BASIC CONCEPTS, INC.**
P.O. Box 355 Forestburg, Texas 76230 (817) 430-8901 Dallas/Ft. Worth METRO
Manufacturer of Porcelain-On-Steel Travel Trailers and 5th Wheel Trailers

We build porcelain-on-steel trailers the old-fashioned way based on integrity, high-level quality and professional competency

BCi introduces its new ... 1989
20-Foot Porcelain-On-Steel Travel Trailer Model*
"The Porcelain Classic"
Fully Furnished With Full Bath And Spacious Floor Plan
*not including tongue, hitch or rear bumper



THIS SLEEK, NON-SELF-CONTAINED 20-FOOT TRAVEL TRAILER BEAUTY WITH ITS ASSERTIVE AERODYNAMIC APPEARANCE, ITS SOLID STEEL STRENGTH AND STABILITY AND ITS UNCOMPROMISING COMFORT AND CONVENIENCE HAS AN INCOMPARABLE 1989 PRICE TAG OF ONLY **\$28,500⁰⁰**

STANDARD FEATURES: All electric; heavy-duty steel construction; requires outside hook-ups for water, sewage and electric; electric brakes; heavy-gauge aluminum exterior siding; reflect-

Many of these businesses ran for decades, but when the original entrepreneur retired the business often had to close as there was nobody to take it over. Or in some cases the new owner was not able to manage it after all. Some of the best products were simply lost, including Granny's laundry detergent, Right On's Crystal sealers, Janice's barrier cloth products, and Francis Simun's three-dozen types of bread.

Finding non-toxic food

Supermarkets did not sell organic or natural foods, and the foods they sold were poorly labeled so it was difficult to know what was in the package. There were no certifications to ensure organic food really was organic.

Finding natural and organic foods was difficult. Health food stores were small and few in number. Farmer's markets were a common source. In the *Human Ecologist* there were frequent mentions of farmers who sold directly to the public.

There was no internet to search for sources. The Center for Science in the Public Interest offered a list of mail-order sources of organic foods. To get a copy, one had to mail a self-addressed stamped envelope to their office in Washington, DC. (HE 34)

An Oregon company advertised their tuna and salmon as "netted far off shore and then packaged in glass" and "used in EI units." This was apparently before it was discovered tuna is a mercury hazard.

An extra problem was that many foods were only available seasonally, so Vera Rea (Dr. William Rea's wife) wrote about how to can vegetables (HE 32).

Finding information

Information that is now easily available on the internet was difficult to find. Small ads in *The Human Ecologist* offered help.

A dentist sold a small booklet with information about the different dental materials, just \$4.75 by mail.

Someone with access to a large medical library offered to research articles there for \$9 an hour.

Some individuals also maintained lists of mail-order sources of different kinds, such as natural clothing, books, etc. The lists were available for a couple of dollars, which were advertised in tiny ads in *The Human Ecologist*.

There were even full guidebooks, such as *Twin Cities Resource Guide for the Food and Chemical Sensitive Person* and *A Consumer Guide for the Chemically Sensitive*, by Debra Lynn Dadd.

Even this early, there were many books available that were relevant for MCS. The magazine reviewed several and periodically listed books and where they could be

ordered from, as well as offering some for sale. These were often written by doctors such as Theron Randolph, Iris Bell, William Rea, William Crook, Lawrence Dickey, Doris Rapp and several others.

People put in small ads asking for information from other readers. That could be about anything, such as suggestions for where to go on a ski vacation to whether Parkinson's disease was related to MCS.

Sometimes these requests for information spelled out the personal tragedies, such as this from a woman in Washington State:

Technical illustrator (45) with 11 years experience and strong background in The Fine Arts has E.I. and must find safe new career/job ideas to survive for the next 20 years. (HE 35)

The press

MCS had a low profile in the 1980s. There were few newspaper articles and TV mentions, but they were almost all very sympathetic to the sufferers. This all changed after 1990 when there was suddenly a lot more media coverage and the chemical industry realized MCS was a threat to them, but that story is told elsewhere.

Sources and references

The bulk of the source material is from the issues of *The Human Ecologist* published 1980 through 1989, including their many ads. They are referred to in the article as "HE" with the issue number. Some other good sources are listed below.

A Texas colony for people allergic to 'everything,' D.W. Nauss, *Dallas Times Herald*, Nov 7, 1982.

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

Environmental illness: are these people truly ill or merely crazy? Allergists and clinical ecologists can't seem to agree, Steve McNamara, *Pacific Sun*, August 5-11, 1983.

Nightmare of the universal reactor, Lee Dye, *Los Angeles Times*, October 30, 1983.

On the cutting edge, Truman Temple, *EPA Journal*, October 1980.

Nowhere left to go, Roy Bragg, *Houston Chronicle Magazine* November 19, 1989.

Sufferers find haven from chemical world, Lisa Belkin, *New York Times*, December 2, 1990

Victims of rare illness allergic to everything, Lee Dye, *Los Angeles Times*, October 30 1983.

More information

More historical information about MCS is available at:

<https://www.eiwellspring.org/history.html>