

A history of popular treatments for multiple chemical sensitivity



With no funding for medical research, MCS patients had to navigate a jungle of alternative treatments. Several became popular for a while and then faded away again.

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About the picture

The picture shows two patients doing oxygen treatment at the Environmental Health Center – Dallas in 1999.

The treatment jungle

When most people get sick they go to a doctor who prescribes a treatment and the problem goes away. End of story. For people with chronic, poorly understood illnesses, the story is very different. Doctors have little to offer beyond symptom treatment.

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American doctors are notorious for minimizing and psychologizing ailments they do not understand, especially with female patients. Besides MCS, that is also the case for autoimmune diseases, chronic fatigue syndrome, fibromyalgia, post-Lyme and many others. Patients subjected to this often lose faith in traditional doctors (O'Rourke).

When people are sick and science has no cure, they often go looking for alternative treatments. Patients and health providers experiment; sometimes the patient reports feeling better; the story travels; other patients flock to try the new treatment. When the treatment disappoints, patients look for the next miracle maker.

Meanwhile, academic researchers sit in their ivory towers and heap disdain upon the frontline physicians whose first priority is to help their patients as best they can. That sometimes means trying unproven and imperfect treatments rather than simply abandoning the patients.

This was the pattern when tuberculosis was incurable, before antibiotics were invented (Jones; Kravetz).

A more recent example was during the AIDS epidemic in the 1980s and early 1990s, as shown in the Oscar-winning film *Dallas Buyers Club*. The quest for an AIDS cure, with all the blind alleys, and academic and political obstacles, is vividly described in *How to survive a plague* (France).

When the nuclear power plant in Chernobyl spewed radioactivity around Soviet Ukraine, doctors and officials told the people stricken with radiation sickness it was just anxiety, and offered no guidance to the population. This gave rise to various remedies people hoped would help, such as alcohol (Higginbotham; Pomerantsev).

Why some treatments become popular

When people try a new treatment, there is often a lot of hope that *this time* it will help. Maybe it did help some of those who tried it first – at least so they felt a little better. Or maybe it was just the placebo effect.

The early adopters talk up the new treatment to the rest of the patient community. This encourages more to try it, and since they have a stronger expectation that it works, the placebo effect is also stronger.

Meanwhile, those who try the treatment and see no benefit tend not to speak much about it. Hence positive stories dominate and drive up the popularity, until it eventually craters.

This effect was especially pronounced during the AIDS epidemic, where people often died within a few months of being diagnosed and thus people frantically tried all sorts of treatments (France). With MCS, the cycles are stretched out over several years, with some treatments remaining popular as there is still no cure available.

Inside such a cycle it is difficult to see whether it is just another fad or not. A more clearheaded evaluation is to look at how many of the people who report success are actually able to go back to a normal life and have a job again. But if it is cheap and harmless, why not give it a try? It's like a lottery ticket.

Maybe many of these treatments actually do help *some*, but they drown in the pool of people. MCS may actually be a whole class of diseases, each with its own yet-to-be-discovered treatment. That would be similar to cancer and infectious diseases which are also classes of diseases with a variety of treatments.

The MCS treatments

A 2003 survey of MCS patients lists 101 different treatments, including more or less alternative types (Gibson 2003). There was also a smaller survey in 1996 (LeRoy). There are many more than those listed in the two surveys.

Talking to old-timers, we have created this list of treatments that were the ones people flocked to at some point, as they were rumoured to be particularly helpful. Many are still in use today.

The list is somewhat in chronological order, starting with the oldest treatments back in the early 1980s.

- Kelp (iodine)
- Nootropil (drug)
- Injection with own urine
- Candida treatment (anti-fungal)
- Coffee enemas
- Blood sterilization (ultraviolet light)
- Amalgam removal (dental fillings)
- Chelation (removal of heavy metals)
- Oxygen

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- Colonics (biome cleansing)
- Neurontin (drug)
- Antioxidants (supplements)
- NAET (Nambudripad Allergy Elimination Technique)
- Various subtle-energy treatments (reiki, etc)
- Marshall Protocol (antibiotics, light deprivation)
- Intravenous antibiotics
- Hyperbaric oxygen
- Brain retraining (Annie Hopper/DNRS, Gupta, Be In Health).
- Mast Cell Activation (drugs)

The two newest treatments, Brain Retraining and Mast Cell Activation drugs, are currently popular. There are stories circulating from people who were helped, while those who saw no benefit rarely speak up.



Hyperbaric oxygen treatment.

This list is for historical information and not an endorsement of any treatment. Several of the later treatments are described by Pam Gibson (2003).

This is not an exhaustive list, some people have tried over a hundred treatments, especially nutritional supplements.

Illicit treatments

In the 1980s and 1990s some clinics opened in Mexico that offered treatments that were frowned upon by the American health authorities. These clinics catered to patients with AIDS, MCS and other incurable diseases (one clinic is portrayed in the film *Dallas Buyers Club*).

We do not have a list of what treatments they offered MCS patients, but auto urine injection is said to be one of them. (The idea was to de-sensitize to impurities in the urine, similarly to regular allergy shots.)

Why is there no cure for MCS?

It takes a lot of time and money to study a disease scientifically. The disease usually has to be well understood before a cure can be found.

Funding agencies, such as the U.S. National Institutes of Health, have to be convinced MCS deserves funding, which will have to be taken from the study of other diseases. Or, the politicians will have to be convinced to fund such studies separately.

Funding is very much a political issue. There are many patient groups lobbying for research money to study their particular disease. There are also commercial interests that prefer MCS to remain a mystery and thus controversial. (www.eiwellspring.org/hist/CMA1990.htm).

Funding research into MCS is the same as recognizing MCS exists, and that is politically unacceptable.

MCS research has been starved of funding much more than other controversial illnesses, such as fibromyalgia and chronic fatigue (Hu). Scientists seeking funding to study MCS have been met with derision (Meggs).

AIDS overturned many established dogmas about infectious diseases, and was thus controversial. But it was hard to explain it away with the dead bodies piling up. MCS is fortunately not that spectacular, but it is easier to ignore.

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More MCS history

See www.eiwellspring.org/mcshistory.html