

The disease which must not be named

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Health authorities, scientists and others pretend that people with environmental disabilities do not exist. Activists trying to do something are ignored. Here are examples.

Keywords: chemical sensitivity, environmental illness, environmental sensitivity, politics, advocacy, activism, civil rights

Mentioning something by name gives it legitimacy. It exists. Therefore people can make a great effort to not use the name when it suits their politics.

An example was during the AIDS crisis in the 1980s. Officials refused to talk about AIDS, even though it killed thousands of Americans every year. At the time AIDS mostly infected gay men and talking about AIDS would thus acknowledge gay men existed.

The same has been happening for decades to people with chemical sensitivities. In many ways there is simply a blackout. The disease cannot be named. It is invisible.

When the American Academy for the Advancement of Science met in 2024, they discussed brain fog in chronic “long” Covid patients and cancer patients undergoing chemotherapy (Economist 2024).

People with chemical sensitivities were not mentioned despite brain fog has been a common symptom there for decades before chemotherapy and the Covid virus even existed. That community created the name “brain fog,” which was until recently named in just a few articles, and then in quotes to signify it was a controversial name.

When the *New York Times* had an article about brain fog (Sheikh 2022), MCS wasn’t mentioned there either. The article listed several measures to try to help, but abstaining from the use of common toxic household products was not mentioned.

Even people with other disabilities

In the 2017 documentary film *The Sensitives*, activist Susan Molloy travels to a major disability conference in Washington, DC. In one scene we see her attempting to get MCS named in a footnote to a policy document, but is rebuffed.

This was the National Council of Independent Living (NCIL), a big organization of people with all sorts of disabilities.

Even other sick people who are also ignored and psychologized by mainstream doctors shy away from mentioning MCS if their own illness is even slightly more “respectable.” An example is the 2022 book *Invisible Kingdom* about how people with autoimmune diseases are psychologized by doctors.

It never mentions MCS, except indirectly in one sentence about the 1995 film *Safe*. But it mentions fibromyalgia and CFS/ME.

The medical journal that never existed

In the 1980s medical journals often refused to publish articles about chemical sensitivities, unless they portrayed it as a mental illness.

To counter this problem, Dr. Lawrence Dickey in Colorado published a new medical journal. It started in 1982 and was named *Clinical Ecology*, the first eight years, and then *Environmental Medicine*. It ceased publication in 1992.

This journal contains a wealth of experiences with MCS patients, but it is not available. No medical database stores it, no medical index lists it. It's as if it never existed.

Ignoring the sick

The community of people with chemical sensitivities has tried to get some attention, but is usually ignored.

About 2015 a dozen activists attended the annual meeting of the Arizona Center for Disability Law. This organization is federally funded to protect the civil rights of people with disabilities. At its annual meeting it sets priorities for the coming year. Besides the leadership, there were only the MCS activists present, either in the room or by phone.

Still, the leader simply kept ducking the pleas for legal help to move the dial just a little on access to medical facilities, etc.

Around 2017 a dozen people with MCS who were living in Arizona tried to get AARP to help. AARP (American Association of Retired People) is a giant national organization that serves the elderly, including through advocacy. The activists were all old enough to join and did, before sending letters to the AARP branch in Arizona asking for help. No reply.

Academics ignore too

A way to get validated that we exist is to be mentioned in various reports, especially those displaying specific numbers.

The Statewide Independent Living Centers (SILC) is a federally funded organization that operates centers around the country to assist people with disabilities so they can stay in their own homes and don't have to be in an institution (of course, institutions do not accommodate people with chemical sensitivities).

Around 2003 or so, SILC was doing a study about whether disabled people have access to medical facilities (a big problem for people with environmental disabilities). The data gathering was done by an independent contractor. Activists contacted the contractor, which sent staff to interview forty people with MCS in Arizona. These were in-person interviews, most of them done in the Snowflake community. It took place at the medical clinic of Jack Rice (since deceased).

Apparently someone later decided to bury all that data. The final report didn't mention MCS with a single word. The data was placed under the category of "Other."

Another attempt was in about year 2012, where the Arizona health authorities were doing a survey of disabled people. They came to Snowflake where they conducted a focus group to decide what MCS-specific questions to put in the survey.

The survey was mailed out and had dozens of questions, including three specifically on MCS. But, again, the final report didn't mention MCS with a single word.

About year 2007, some professor at the University of Buffalo asked for people with all sorts of disabilities to comment on various measures to make public spaces accessible. We got about fifteen people to fill out the detailed questionnaire, pointing out how the measures did not at all help people with MCS. The study report didn't mention this by a single word either.

These studies were all paid for with government money, so they are not allowed to discriminate. Rendering a group of disabled people invisible is a form of discrimination.

"Universal Access"

There is a set of guidelines called "Universal Access," that intends to allow people with all sorts of disabilities to function in the workplace and society just as everyone else.

But it is a mis-nomer, as people with environmental disabilities are ignored and excluded.

Many many more

There are many many more examples of this silent treatment, the ones listed are just the ones we are intimately familiar with.

Sources

Most of these events were witnessed by the author. The remaining were provided by Susan Molloy.

Unfortunately, we didn't keep records of these attempts, so had to go by memory, especially which year it was.

References

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2024