

## How to make a living when you have multiple chemical sensitivity



**If you have chemical sensitivities (MCS) and can no longer work your regular job, yet you are rejected for disability, here is what other people did to earn an income, or supplement their meager disability.**

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Getting sick with multiple chemical sensitivity (MCS) makes it difficult to hold onto a job. With mild MCS it may be doable, but with severe MCS it gets tougher. The disease can get worse over time, but often it does not.

Discrimination, indifference, and harassment can force people out of a job they could still do if the boss and colleagues would be more flexible. In that situation the law should be on your side, but real life may not be so kind.

## **The case for hanging on**

If you currently have a job, it may be the smartest to hang on to it, even if it is really tough.

In the United States the Federal Social Security Disability Income (SSDI) program does not pay very much. Larger corporations often have their own supplemental disability insurance program to add to the meager SSDI. If your health is sliding, it may be better to tough it out to retain that coverage. (Policies vary, but you'd usually have to be employed by them for some years before you are eligible.)

If you are currently in a State job (State administration, university, police, teacher, etc.), you may not be eligible for SSDI at all, but must apply for the local State plan. If you leave such a job for one that is covered by Social Security, it can take several years before you have coverage again.

People have left their well-paid jobs to take a "sabbatical" in the hope that without getting sickened on the job every day they would recover. Others have left for poorly paid part-time jobs, also in the hope that they would get better. They paid a high price, as when their health further declined, they were then only eligible for SSDI.

We also know one case where the person quit working and postponed applying for SSDI for too long. After some years of not working, you are no longer eligible to apply.

There is a stop-gap program for disabled people who can't apply for anything else. Called SSI, it does not pay enough to live on, but it does come with health insurance.

You must stop working before applying for SSDI or SSI. If you are working, you will be denied on the grounds that you are able to work, since you are working. They do not consider how tough it is to work. There are no grey zones.

Be aware that for some people, ongoing toxic exposures can make the sickness worse. If you notice that your health keeps sliding, your current job may be too damaging.

## **On-site employment**

We know a number of people who changed to jobs that worked for them, as they "naturally" involved a cleaner environment.

One became a ranger at a national park. He chose Big Bend in West Texas. It had a dry climate, the air was very clean, and there were not many tourists. The buildings were old, he spent hours every day outdoors and he could use older offgassed patrol cars.

Another man got a job as the attendant at a recycling station. This was in Europe where such stations are big outdoor operations where people walk a short distance from their cars (this may not work in the US, where cars drive right next to each dumpster).

Some people have gotten jobs on organic farms. One of them has a part-time job tending a grove of organic fruit trees.

Some have gotten jobs in health food stores, as they tend to be more health conscious. In one store they sold scented soaps, but they accommodated her by placing them inside glass “cheese bowls” (which she had to pay for).

Dr. Rea’s Environmental Health Center in Dallas employed multiple people with MCS. Perhaps a local holistic clinic is an option?

### **Self-employed**

If you are your own boss, you set the rules yourself and it is a lot easier to control your own environment. Most commonly it is some sort of freelance work, perhaps even a variety of work depending on what is available.

A hair stylist got an agreement with a large hospital that she could offer haircuts to patients in their rooms. This is especially popular with bedridden patients. Later on she created her own one-chair salon inside the hospital. This was in a very large hospital in Dallas that did not use fragrances much.

Another hair stylist opened her own chemically-free hair salon in a Danish town. She serves regular people, and also has several MCS customers. Some travel to her salon from far away to avoid the usual chemical onslaught.

She asks her customers up front to not wear fragrances, and the day before the appointment she sends a reminder to their cell phones (text/SMS). If they still show up fragranced, they may be asked to remove their outer layer of clothing and wash up in the bathroom. Winter coats may be hung outside. This works well, but may not work outside the compliant culture in the Nordic countries.

A woman in the Midwest goes to yard sales to pick up items she can clean up and sell online. That can be anything from collector’s coffee mugs to small appliances.

Yard sales in upscale neighborhoods are often the best places to go. But you need a good nose for what will sell, otherwise you can end up with a garage full of worthless junk.

One person knows a lot about antique furniture and lives in New England where there is a lot of that. She goes to yard sales and estate sales where she buys pieces cheaply, which she sells online to collectors. She hires a skilled carpenter to do minor repairs. She does some refinishing herself while working outside and wearing a respirator.

Selling things at outdoor flea markets and farmer's markets may work, since it is outdoors. In some states you do not need a certified commercial kitchen if you sell home-made food items at such markets. We know one woman with MCS who tried to sell home-made kimchi, but she had few takers in her rural part of Arizona (a college town might be better).

One person bought houses and lived in them while fixing them up to be healthy houses. She then lived there until she found someone with MCS who was willing to pay a premium price for such a house. This is a high-risk enterprise — MCS houses are slow to sell, you need to make good choices which houses to buy, and know what to do. It may also require you to live in a car, trailer, shed or sealed bathroom for several months.

Some sort of mail order business may work, if you can develop a product that will sell. A few decades ago several people sold specialty products for people with MCS (renovated trailers, air purifiers, ozone machines, paints, soap, etc), but there is less of that today.

With the demise of the nationwide MCS newsletters, it has become more difficult to advertise products specifically to people with the illness. Currently, social media sites do not offer advertisers a way to target people with MCS.

### **Self-employed with hired staff**

We know of one man who owns a small business with a few employees. He asks the staff to not use fragrances and requires them to wear a work uniform. The staff put on the uniform when they arrive and take it off before they leave. He washes all the uniforms himself. This solves the problem with fabric softener and scented detergent.

Another business owner has one employee who does the paper work. She does all the work from her own home and just meets him in person a couple of times a week. They meet outside if the weather is fine, so he doesn't have to breathe in her

fragrances. Many times they meet at a picnic area in a small park halfway between their homes.

## **Work at home**

Many large employers now allow their staff to work from home, though currently most of them do want the staff to come to the office at least once a week. This builds “corporate spirit” and does help create the informal connections between the workers that are important for cooperating on projects.

Some people do various freelancing work on their computer, such as typing, editing, indexing, researching, and web design. Look at gig sites on the web for ideas of what other people are doing and how well it pays. Some is paid well, some very poorly. For some of these gigs you will be competing against people in low-income countries. If you live in a high-income country it helps to emphasize your knowledge of local culture and language. It is also much cheaper to ship materials when it is inside the same country.

One person has excellent visual-art skills and works for a company doing written descriptions of photos. With the rise of artificial intelligence, such work may soon no longer be available.

A common MCS-job is medical transcriptions. This is typing reports dictated by physicians into recording devices. This sort of work requires going through a training course, which you have to pay for yourself. Artificial intelligence may automate such jobs away soon.

Another person is bi-lingual and does translations of corporate promotional materials for brochures and websites.

We know people who have worked for marketers that sell through television ads, television infomercials or telethons. The “call now” toll-free number on the screen is routed to people sitting at home. It was poorly paid, and the computer routed most calls to the people who were best at “upselling,” while newbies and those with less aggressive sales personalities had to stare at a silent phone most of the time. It’s a ruthless business, and you’ll be at the bottom of the pecking order.

Be cautious about unskilled “work from home” schemes that require you to invest in products and other up-front expenses. Those are often scams of various sorts.

## **Highly skilled self-employment**

If you have the credentials of an architect, lawyer, engineer, physician, social worker or similar, your skills give you more flexibility. We know several people who support themselves working part time in their profession.

Some meet clients in person. If a client is too toxic, it may be necessary to refer them to a colleague.

Some meet clients exclusively via phone or computer.

Due to the stigma, few of these professionals ever reveal their disability. That can severely damage their reputation, which is very important for these sorts of services.

## **How to look for a job**

Take a personal inventory of what you are good at, and what you find interesting to do. Be creative, don't just focus on what you have been doing so far. You are much more likely to find, and be hired for, a job you are motivated to do, than one you would hate.

A lot of jobs are filled by informal contacts. If there is a place you really would like to work, ask if any openings are coming up. Maybe befriend an employee who can look out for you. Let people know you are looking, and what you are looking for.

Before you apply, consider visiting the workplace incognito to see what the air quality is like. If there is a receptionist or such to block your way, think of some excuse to chat a little (saying you are lost may not work in this age of GPS navigators, but you might ask for directions to somewhere else in the same building).

## **Whether to tell at a job interview**

If you go through a job interview, you do not have to tell them you are disabled, and they are not allowed to ask, according to the law in the United States (and probably many other countries). Legally, they cannot reject your application because you are disabled, but studies show that if they know, then they are less likely to offer a job.

Whether to volunteer that information or not depends on the situation. In some cases it can help you gauge whether you want the job or not, depending on how the prospective boss reacts. Regardless of what the law says, if you need

significant accommodations it may not happen. They are not required to meet “unreasonable” requests. What is “reasonable” is very fluid, a large company may be more able to accommodate than a small one.

If you decide to disclose your disability, a good time may be if you are asked why you applied to work for that particular outfit. Think about how you’d respond to that in a positive way.

Also be aware that employers are reluctant to hire someone who has not had a job for a long time. They know people tend to lose basic job skills, such as showing up on time, accepting directions from the boss, and being productive.

### **It is not wonderful**

These stories may seem positive, but it is still tough and some people have MCS so severely none of this is realistic. When people feel sick on a daily basis, then no arrangements may work. There are people in that situation who are still denied disability, or have not worked enough years to qualify.

Disabled people usually have to accept a reduced income, sometimes very steeply so. That is one of the many things outsiders don’t realize (including many doctors).

Some of the people we talk about here did have other incomes, but barely enough to live on. Some came from spouses, friends, family, churches, etc. For some people that is all they have.

Some people have to scrape by using various forms of government assistance, such as housing vouchers, food stamps, and Pell grants. It is possible to do, but very tough.

Some end up homeless, typically living in a van. We have met several, including one who begged for money in front of a grocery store in Flagstaff, Arizona.

### **More information**

For more articles about managing environmental illnesses in the workplace, go to [www.eiwellspring.org/workplace.html](http://www.eiwellspring.org/workplace.html)