

## **How people with chemical or electrical sensitivities handle the caregiving problem**



**The system of assisted living, nursing homes and home care is a nightmare for people with environmental illnesses (EI). We here describe how they actually handle the situation when long-term care or end-of-life care is needed.**

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Caregiving is taking care of a person's needs, whether it is just for shopping, or is much more involved. It includes taking care of someone dying, or who is elderly and frail, or someone who has spinal injuries and is in a wheelchair.

In the United States, most caregiving is done by relatives, especially spouses and children. But that option is not available to many people with environmental

illness (MCS or EHS), since many do not have children, and the difficulty of living with the disease very often breaks up families.

The regular system of nursing homes, assisted living centers, adult day cares, and other services are usually not willing to keep people with environmental disabilities safe. They simply are not. Doing so would require changes to how they do things, and perhaps also the personal choices of caregivers (and other people present).

Since the EIs know very well how unwelcoming all parts of the medical system are, they tend to tough things out on their own as long as possible. By the time they ask for help, it often won't be needed for long.

### **Staying at home**

By far, the best is for people with environmental disabilities to stay in their own homes, where they have much more control over their environment. They can choose what laundry and cleaning products work best, and the number of people entering is greatly limited.

Staying at home is also much better for regular people. The U.S. Supreme Court agreed in its 1999 *Olmstead v. L.C.* ruling, that specified the States must make that possible, as long as it is feasible.

The Arizona District Court strengthened that in the case *Peg Ball v. Anthony D. Rodgers*, against the Arizona health care system for people living on a low income.

### **Less-toxic caregivers**

The other part of staying safe, is that those who come to the home to help must refrain from bringing along noxious chemicals and wireless devices.

Unfortunately, the use of toxic chemicals is considered so mainstream that most people will balk when asked to refrain from using fragrances, fabric softeners, styling gels, etc. And to leave their mobile phones in their cars.

Some people have been able to convince the caregivers to switch to less-toxic products. Since these products often cost more and are not conveniently available, the disabled person may need to buy and keep a supply to simply give to the caregivers.

If the caregiver uses a laundromat, the clothes will often be contaminated by the machines (especially a dryer that recently had a dryer sheet in it). If the caregiver lives in a house with a washing machine, you'd have to supply enough laundry products for everyone who lives there, it probably won't work for them to switch between two sets of products.



*Caregiver wearing clothes and hairnet provided by the client.*

Some have managed by having special clothes for the caregivers to put on when they arrive, and take off before leaving. That can be a set of regular clothes (they keep their own underwear, and possibly socks). It can also be a disposable painter's suit they use to cover their own clothes with. These clothes never leave the house (they would otherwise become contaminated, it just doesn't work).

For days where the hair is too toxic, keep a hairnet, shower cap or similar on hand. If the person has long hair, it helps to braid it to reduce the surface area. Perhaps the braids can also be tucked under a hat.

Expect a lot of frustrations when going through the education and cleanup process. It is also frustrating for the caregiver who really tries, but doesn't succeed on multiple tries. It is not easy for them either, people who live the toxic lifestyle can't tell the difference. This writer once talked to a hired caregiver who stated she lived without fragrances, despite reeking of them, and that was while standing outdoors.

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It is hard to understand that when using fragrances on the weekend, it doesn't wash off again Monday morning. And that it takes months before a heavy user of fragrances clear out the chemicals stored in the body fat.

Unfortunately, many hired caregivers simply won't even consider doing any of this.

These kinds of jobs are a lot of work and poorly paid, so there is a high rate of turnover. Then you start over again.

### **Community caregiving**

In areas with a larger EI community, there are usually regular people who do work for the EIs (such as shopping and cleaning) and therefore are at least somewhat less toxic to be around. They accept the problem as "real," which is a great help.

Success stories include hiring the wife of a handyman who did a lot of work for the local EI community. Another hired a woman who worked in a small health food store that had a lot of customers with EI.

In Tucson, Arizona, there is a large EI community with an active support group. When one of their members was dying of cancer, four of the people with MCS stepped forward to share the caregiving. They were functional enough to do it, and since they already lived the non-toxic lifestyle there were no cleanup problems. They were able to do the caregiving until the final stages where the local hospice team had to be involved too (some were toxic, some were not).

A problem with community caregiving is to pay for it, if money is limited. The social services may balk at paying people who are not vetted and controlled by them. It may be possible to get a lawyer from a legal aid outfit to argue it is a case of accommodating a disability, but we are not aware of anyone who tried.

This author does know two people who committed suicide when their savings ran out and they could no longer afford to pay for their needs.

### **Live-in caregiver**

Some people with a spare bedroom offer free rent in return for doing household chores. The caregiver has the same environmental disability, so there will be a lot less conflict over the lifestyle restrictions than with a regular caregiver.

This can supplement the meager disability benefits received by the caregiver, without triggering a review. And since safe and affordable housing is so scarce, this could be a real win-win situation.

Such opportunities are sometimes advertised in newsletters.

It is important to thoroughly discuss ahead of time what is expected, both in terms of lifestyle (use of chemicals, etc) and the work. The caregiver should not be expected to be available at all times, day and night, seven days a week. The number of hours must be reasonable. There must be days off.

Find out what the rent is worth. Then divide that with the hours worked per month, so you get the hourly pay. Contact a local social service to find out what caregiving normally cost. It may be necessary to pay for the caregiving besides providing the free rent.

Do have an emergency backup plan in case the arrangement doesn't work out. The caregiver might leave with very short notice.

### **Modifying the home**

A regular home can be modified to make it safer and more usable for people who are in wheelchairs, or not steady on their feet.

The furniture should be sturdy enough, so they can be used to grab onto to prevent a fall. No flimsy folding chairs. Grab bars can be installed on the walls in the bathroom, especially next to the toilet and by the shower.

Doors can be widened, so a wheelchair can pass through.

Thresholds under doors can be removed, so wheelchairs can pass and unsteady walkers don't trip over them.

The sinks can be modified so they can be used from a wheelchair. If there is a cabinet below, the doors can be removed and the bottoms cut out to make room. The drainpipe under the sink can be wrapped to prevent scalding from hot water, especially if the person does not have a good sense of hot/cold on the legs.

Remove throw rugs and other items that can be tripped over.

Replace door knobs with door handles.

There are many other modifications that can be done to make the home safer and usable, depending on the need. This is a mainstream issue with lots of resources available.

Modifications can be costly. Financial aid may be available. In the United States, this is tax deductible as medical expenses, though be aware the combined expenses have to exceed a threshold.

### **Nursing homes**

Sometimes the only option is a nursing home, when the need for help is greater than what can be provided at home.

That happened to a married couple in northern Arizona, where both had severe MCS. The husband needed round-the-clock care, which the wife could no longer provide with the few resources available in their rural area. Thus began a difficult journey.

She visited several nursing homes and eventually settled on one in Phoenix, two hundred miles away. When that didn't work out, she had to move him to another, and another.

The difficulties were many. The staff used toxic laundry products and would not consider anything else, even just for him. She had to do his laundry at home and drive it to the nursing home.

One place insisted on using a special anti-bedsores mattress, which was made of some sort of super-toxic foam.

Fragrances, noise, and various medical equipment were ongoing problems.

He was too debilitated to speak up for himself, so she had to be his advocate, which was a constant task.

Eventually, she found a nursing home that was somewhat acceptable.

Another person with MCS also went into a nursing home. When she "complained too much" a doctor came in and gave her a drug, which he said would make her feel better. It was some sort of psych drug, given to shut her up, which is not uncommon in nursing homes. She died soon after, which was not expected. It was probably the drug that killed her. People with MCS usually have trouble with psych drugs.

Another person was given a room next to an in-house hair salon, with all the toxic drift through the open doors. The management refused to move her to another room.

It is common that the nursing home staff thinks that environmental illness is just a delusion, caused by dementia. The “solution” is drugs.

There have been a few somewhat positive stories. One woman reported that she could not get them to use non-toxic cleaners, but they were willing to wheel her out on the patio for some hours when they did the weekly cleaning. They were also willing to keep the door to her room closed at all times, so fumes didn't roll in from people in the hallway (doors are otherwise kept open all day for staff monitoring and convenient entry).

### **Checking out a nursing home**

If there are several nursing homes available, go visit all of them. They are not all the same.

What does the place smell like? If it smells of urine or feces, that probably means it is understaffed and the residents not cared for promptly when they wet themselves. If it is heavily fragranced, perhaps they are covering up their lack of proper care.

Look for spots on the ceilings that might show a roof leak that wasn't fixed in a timely manner, and which now may harbor a mold colony.

Can the windows in the rooms be opened for fresh air? Are they allowed to open them?

Is there an outdoor area where the residents can get fresh air (such as during cleaning of their rooms)?

Look in the laundry room. Do they seem to use dryer sheets?

Do they require all residents to wear some sort of wireless monitor? (On wrist or around the neck.)

What is the food like? Are there options for those with food allergies?

Meet with the manager to discuss the special needs for someone with environmental disabilities. Be aware that vague promises are often not kept. Try to be specific, and discuss how to solve the problems in a constructive way.

### **Advance directives**

People in nursing homes, or cared for at home, can become so debilitated that someone else must make the decisions. Traditionally, that falls to the immediate family. But that may not be possible or desirable.

Many EIs never had children. They may have moved far away for a healthier climate. Or what family there is, may have become estranged as a result of the disease. Some family members falsely believe the illness is purely psychiatric, and would authorize dangerous drug “treatments.”

Hospitals and nursing homes may restrict visitors to just the close biological family, barring long-term friends who genuinely care and try to help.

To counter all that, it is possible to leave instructions ahead of time. There are many options. The most important is Power of Attorney for Health Care, which is a document specifying who is authorized to make decisions when the sick person no longer can.

Blank forms are available on the internet. Make sure to get one legal in your state. You can change it as often as you like.

### **More information**

The AARP (American Association of Retired People) has a website with more information about nursing homes, caregiving, etc.

More information about caregiving and eldercare for people with environmental illnesses on [www.eiwellspring.org/healthcare.html](http://www.eiwellspring.org/healthcare.html).