

Living in a community of people with environmental illnesses (MCS/EHS)



There are many benefits to living around other people with environmental illnesses, whether it is in a dedicated apartment building or a cluster of individual houses. There are also a few pitfalls.

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Housing is one of the biggest problems facing people with environmental illnesses (multiple chemical sensitivities, electrical hypersensitivity). Not only must the home be safe in itself, but it helps a lot if the neighbors are too.

When the neighbors are not into the chemical/wireless lifestyle, there is no need to constantly dodge their dryer exhaust, Wi-Fi, and other problems. And there is the opportunity to have a social life.

There are communities where people live next door to each other, and communities where people's houses are more scattered.

Clusters of like-minded people are common

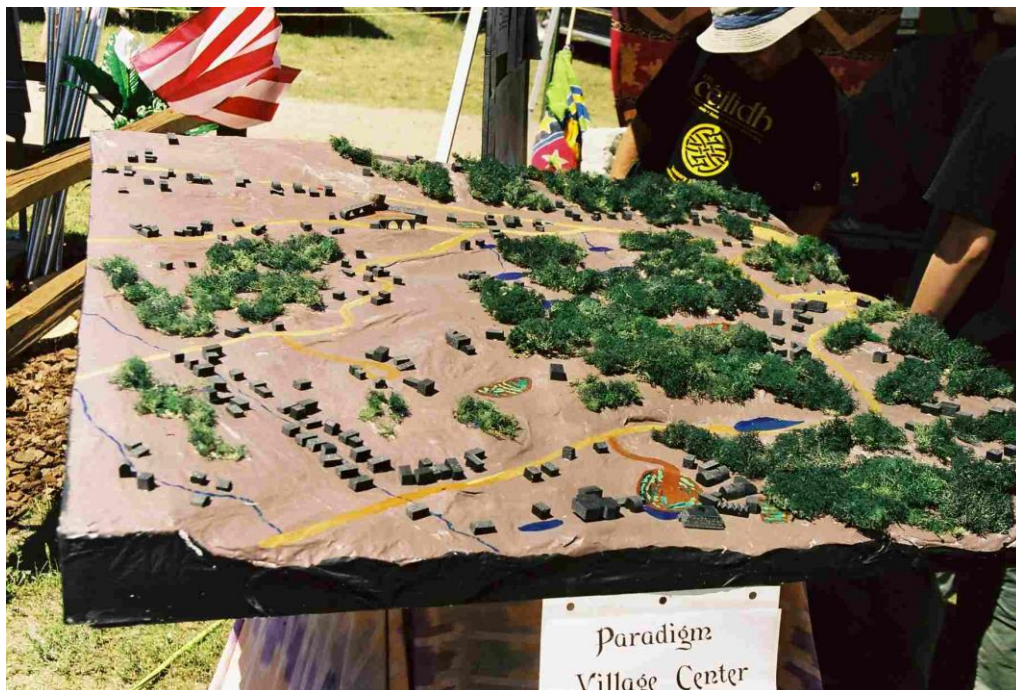
For thousands of years people have wanted to live around like-minded folks. The most commonly known examples are probably the Chinatowns, Jewish neighborhoods, and other ethnic clusters in America, but it is a global feature. In parts of the Middle East, Africa, and Asia there are neighborhoods of Western expatriates, Christians, and many others.

Intentional communities

In America there is a movement of “intentional communities.” Many of them espouse “green” values, some even call themselves “ecovillages.”

Intentional communities can be large or small. There are many versions, from a group of college kids who share a house to a large group of people building homes on a big piece of land.

Such communities are started by a small group of people who try to attract other people and resources to make it happen. Many such projects never get off the ground.



Conceptual model of Paradigm Village.

One large intentional community that didn't make it was Paradigm Village, which was to be built in the Ozarks of Arkansas. The houses were to be clustered

according to their owner's interests, such as meditation or playing musical instruments. A conceptual model of Paradigm Village is shown in the picture above, which was taken at a presentation in 1999. When this author asked whether people with MCS were welcome, it was clear we were not.

There are people with MCS or EHS who live in such communities, especially those with a "green" focus, but there are still problems and conflicts. "Green" and "EI safe" are not the same thing. Burning firewood and using essential oils and wireless gadgets are usually considered wholesome in such places.

It seems most practical to create separate communities for the environmentally disabled.

Breaking the social isolation

Regular people are too often extremely attached to the toxic-and-wireless lifestyle. Advertising has programmed most people to think they have to smell of something, and their houses have to "smell clean," despite that really clean has no smell.



A Fourth-of-July party at an MCS/EHS community in Arizona.

Loyalties to specific brands are also very strong; billions of dollars are spent every year on building these loyalties.

The wireless lifestyle is intentionally made very addictive; people feel naked if they are not constantly connected. Asking them to power down their gadgets is often seen as a big concession.

A community of people with environmental illnesses can offer a social life without constantly having to push against the addictions and habits of contemporary life. It allows you to be among others where there is not the ongoing need to explain yourself to people who simply cannot comprehend.

A community is an excellent way to break the social isolation imposed by these disabilities.

Helping each other

If your car breaks down on a road in the city, in all likelihood nobody will stop and help you. If the same thing happens on an empty dirt road in rural America, the first car that comes by will likely stop.

In small communities there is an unspoken rule that if I help you, then you should help me some other time. This also goes for EI communities. If you break a leg, your neighbors will likely help you. That is less likely if you barely know your neighbors since you can't be near them and their plume of chemicals and radiation.

Hospitals are unsafe places to be, so you'll likely want to get home as soon as possible, but that may not be realistic if nobody will help you with groceries, etc.

If you need ongoing help, maybe some of the neighbors are willing to work for pay, to supplement their disability income.

Hiring regular people, or using helpers sent by social services can be dicey. Most will not change their chemical lifestyle to accommodate you, and the legal system decided that is not a reasonable request (according to one court case).

However, if there are several people needing help, there may be one or two regular people who then become willing to clean up their act in order to serve the community.

This issue becomes more important as we age since assisted living centers and nursing homes are terrible unhealthy places and the "solution" to "difficult" residents is too often the use of calming medications.

There are many other ways people with environmental illnesses can help each other, such as sharing information on the least toxic hair salon or car mechanic in the area.

Acceptance

If you are not the only person with MCS or EHS in the local area, then it becomes less “strange” in the eyes of other people. If you are not the only person who wears a respirator in a toxic store, or you are not the first person to ask a shopkeeper to serve you outside, or if you need the staff at the local medical clinic to call you in from the outside when it is your turn, it’s a little easier.

Knowing you are not the first to ask for these accommodations of your disability may give you the courage to ask, when you otherwise didn’t dare and had to suffer.

And if you need to ask at a place where they haven’t heard about this before, it is a lot more effective if two people are doing the asking.

Opposing developers together

If a developer wants to build something awful on the empty lot next door, that can literally drive you out of your home.

If the project can drive multiple people out of their homes, that carries a lot more weight than if it is just one person saying so.

The developer will not care, but if multiple people show up at the Planning & Zoning hearing, they may at least think about it instead of rubber-stamping the project right away. That buys you time to get more organized and hopefully be able to convince people in the surrounding community to show up at the next hearing. These things are all about how many people are upset enough to show up in person. The politicians know how easy it is to sign a petition, so they care little about that.

Just be careful about not upsetting the surrounding community. You want them on your side, or at least neutral in the matter. If the regular people see a benefit in the new project, that is not good.

Relations to surrounding community

The surrounding community will not react favorably if who they see as outsiders come in and start telling them how to live their lives. This is especially the case with small communities in conservative areas.

Upset neighbors can make life difficult in so many ways, once they know your weaknesses. It can take many forms, such as burning trash, drying clothes with dryer sheets or barbecuing greasy burgers when the wind direction is the worst possible. There can also be more overt harassment, such as dumping trash on your driveway.

All it takes is one person upsetting the neighbors. Then they will stereotype it to apply to everyone with the disability.

There have been multiple incidents where newcomers did activist work that was not received well. One glaring example was when an MCS community was forming in southern Utah. One guy from California was used to doing activist work where he came from; in Utah he applied his skills to advocating for a new national monument in the area. The locals saw that as a threat to their livelihoods. The national monument was created by President Bill Clinton, but the nascent MCS-community was pretty much driven out of town.

There have been problems with EI activists wearing out their welcome in a few other places as well.

If you want to do activist work, do it outside the local area unless the issue is truly vital.

Moving to a community

There are so few EI communities in the world that most people have to move long-distance to join one. That is a leap of faith, as it means moving away from friends and family – away from their company and support.

For many, that is too great a leap. Instead, they continue to live in places that barely work for them. Some move back to their parents' house, and perhaps stay there for decades.

Becoming disabled means loss of income from work, replaced with whatever meager pension one might qualify for. Young people who have not worked much may not qualify for any disability pension, but have to subsist on miserly poverty assistance.

There are only two housing communities in the United States, and one in Canada, for people on a low income who have MCS. They have long waiting lists.

Rooming with relatives may be the only option, but it is not easy, especially if they do not accept the illness.

Some people have been able to raise the needed money in creative ways to be able to buy or lease a home in EI communities. These often involve the parents or siblings who put a mortgage on their own houses and then lend the money to the sick person, or they buy the house and rent it out. Some have used government programs that provide housing loans to people with disabilities. See elsewhere on this website for more on financing EI homes.

People with MCS and EHS living together

People with environmental illnesses have a lot in common, and those with severe MCS or EHS tend to have both illnesses, though one may be milder.

But people are people. When a person gets severely sick with MCS or EHS, they do not somehow become a saint. They can be as self-focused and bigoted as everyone else.

Even those who complain about how regular people hurt them with their toxic personal care products can be very reluctant to use a cable for their computer instead of a wireless connection.

And people with severe EHS can be reluctant to stop wearing fragranced products. That is just how a lot of people are, regardless whether they are sick or not.

Any sort of housing intended to accommodate people with MCS or EHS will need to keep this in mind.

Projects intended for people with just one of these disabilities should still keep it in mind, so those with both can be there too. With so few housing options available, they will come and they will try to make it work.

The case for rules

People don't like rules, especially in an individualistic culture like the United States. When four rental houses in Snowflake, Arizona, opened in 2008, there were no rules. The non-profit managing the houses refused to set rules. It took less than two years, then they had rules. There were too many problems without them.

One unexpected problem was that an early resident was a smoker. That is rare for someone with MCS, but this guy had mostly other disabilities, while his MCS was mild. When he was told the new rules required him to step outside when smoking,

he quickly moved elsewhere. He lived there just a few months, but it took well over a year to offgas the house so it could be rented out again.

There are people with MCS who are not bothered by fragrances (one study found fourteen percent). Some of those people are not interested in paying premium prices for fragrance-free cleaning and personal care products. But if they don't, the dwelling will be contaminated when they move out again.

Many of the apartments rented out by Dr. William Rea's Environmental Health Center in Dallas became moldy. That happened because several renters didn't tolerate the heating system and didn't heat their apartments in the winter. The result was condensation of water vapors inside the walls, which caused mold to grow there. Eventually Dr. Rea had to sell them off.

The Ecology Housing EI camp in Seagoville, outside Dallas, housed people in little pavilions. They all shared a building with a kitchen, refrigerators, and washing machines. To give people a break from the drone of the washing machines, they could only be used in the daytime and not on Sundays. Simple rules can help.

Covenants

Covenants are rules placed on land and property. This is done when subdividing land. They could stipulate that people are not allowed to burn trash, use stoves that burn wood, coal or pellets, use fabric softener, etc.

One covenant stipulated that at least one person in the house must have MCS.

The problem with covenants is that a bank may refuse to loan money for buying the house as they cannot easily foreclose and sell the house.

Covenants may be challenged in court and thrown out by a judge who finds them ridiculous.

Sharing bathrooms

At Ecology Housing they had one pavilion where two units shared one bathroom. It caused so many conflicts over incompatible products that the two rooms had to be rented out together to one person only.

However, at an MCS rooming house in the town of Seagoville, up to three renters shared one bathroom. But the landlord had to stipulate which products were acceptable.

Selling the houses

People can decide to move away again for many reasons. They may miss their family too much, or they have family obligations. Some people get better and want to move back. Others may be disappointed in the community, perhaps they didn't make new friends.

The premium price on a healthy home should encourage a sale to someone else who is sick, and it is the kind thing to do, but sometimes there is no buyer who can afford the house so it sells to a normie.

If the owner of the house died, the heirs may just want to cash in as soon as possible and not care about anything else.

Losing a well-built house to a normie is sad. It has happened that it was later "bought back" by another person with EI, but often the house becomes contaminated and unlivable.

If planning an EI community, keep in mind that the houses may not always stay on EI hands. Don't place them too close together.

Covenants that ban the use of wood stoves, fabric softeners, and wireless transmitters may help, but they may not hold up in court.

Afterthought

Living among other people with environmental illnesses can be a boon, but keep in mind that we are not all the same. People need more in common than an illness to be close friends. People can have as diverse opinions about politics and everything else as the regular folks.

More information

More articles about housing people with environmental disabilities on www.eiwellspring.org/multiunit.html.