

Mail to Snowflake



The environmental illness community near Snowflake, Arizona, is contacted weekly by people with severe MCS/EHS. These are the stories they tell in their own words.

Keywords: Snowflake, Arizona, MCS, EHS, stories, testimonies

The Snowflake environmental illness community is one of the oldest and largest in the world. Situated in a rather remote part of the Arizona high desert it offers very low levels of air pollution and electropollution. It also offers a social life with other people in the same situation. And sometimes there are healthy houses available for sale or rent.

The community maintains an e-mail address that allows outsiders to contact a representative of the community. The following is a collection of excerpts from

initial-contact e-mails received over a two-year period; allowing these people a voice in their own words.

The vast majority of these people have severe cases of MCS or EHS. What they have to say may be rather shocking to readers who do not have the severe form of these illnesses themselves.

Sharing

Most of the e-mails included something about the sender's situation, so we knew they were "one of us," and they expected we would really understand as only a fellow sufferer could.

One person even explicitly stated:

Here is my story in case you are interested/concerned that I'm not earnest:

Most sharing was just a paragraph. A few much much longer. Here are parts of what nine different people wrote:

I've gotten my food intolerance under control but it's clear that there are environmental factors that I can't do anything about. I had to move in with my father and he doesn't seem to believe that I am sensitive to things. ... My mom doesn't understand either and comes over with scents on and gives me a hug, I hate that my first thought when I see her is, "shit, where's my facemask?"

My name is [name] and I couldn't believe your description of, "Most of us avoid cell phones and when we come home from town most of us take a shower and put on clean clothes. While in town, our hair and clothes will pick up fragrances and other contaminants, which will have to be removed before we can start feeling better again." That's how we live!

Unfortunately, I have no family able to provide a clean place for me to live, nor do they understand or have tolerance for my condition.

I am 33 years old and have been struggling with severe mcs and emf for roughly 10 years. I have run out of options and am basically homeless at this point. My safe home was in my parents basement and I can no longer live there due to a new router that's making me severely ill. My mother refuses to turn it off and doesn't believe my struggles.

I have MCS and issues with EMFs as well as a "museum full of other health exhibits" as my doctor calls it.

I am in a tough situation. Heard that one before, eh?

My mom has begun using an extremely toxic laundry soap, even though I have repeatedly asked her to use the free and clear soap I leave available. Even though I have tried to convince her of my need, ...I asked her to allow me to take the fragranced soap to give away at the thrift store, but she refused.

Hi, I'm sorry to bother you, I'm getting really desperate. I've had MCS since I was a kid and the last many years it's been getting worse. I'm exhausted. I only have about 2 hours to 3 hours where I can reasonably do anything during the day. ... My life right now is really miserable, and I'm desperately trying to get in a place where my body can rest. I haven't been able to sleep through the night in about 5 or 6 years. If I could even come and camp for a few weeks, that would help me so much!

I can't even think straight enough to make a decision of where to go, but just know Portland is not working.

Housing

People looking for housing is a big theme in the e-mails. Most queries are for rentals, as few have the money to buy a house. Unfortunately, rentals are usually very scarce.

I am looking for a small safe home for rent or sale.

Hello my name is [name] I am 27 from NJ, I am beginning my search for refuge from EMF. I was wondering if you knew of any rooms for rent in the area or maybe a spot to make camp with an RV I would purchase, thank you for your time

I am desperately looking for housing for me and 38 year old daughter. She has been severely disabled due to extreme EMF/MCS ... She has been living in a tent for over a year. Unfortunately, we are on our second location in one year and it is not working out.

If you could please contact me as to whether or not you know of a rental becoming available, that would be great. Even if there aren't any right now, I would love to speak with someone about housing ideas in your area. Building a small safe house is another option I am considering but I would like to rent and get to know the area first.

A young optimist wrote:

Hey! My name is [name] I'm 26 from [city]. MCS has greatly diminished my quality of life though I believe with a few months in a healthy environment with healthy food I can get "better". Do you have any space available for rent?

One person needed a safe place to stay while renovating the house:

I am an MCS person who needs a place to stay while my house is painted. I need at least 2 weeks, but would be happy to pay for a month to get a safe place to stay.

Community

Some also mentioned that a real community sounds enticing. A place where a social life is possible without constantly having to dodge other people's toxics while being doubted those things can be such a problem.

I would love to be in a community where I could relax knowing that there wouldn't be any surprises environmentally.

I was curious to reach out to you because I have been craving to live in an MCS-friendly community for a very long time.

We live in Canada and are travelling down to Mesa for a visit next week. Our 19 year old daughter has extreme EHS and we would like to check out your community. ... our daughter has NO social opportunities at all and lives isolated at home. We would like to investigate a place where she may have the opportunity to see faces other than her immediate family's.

My daughter, [name] age 29, suffers from EHS/MCS... She would like to visit with people in the same situation. We live on a ranch in [location] but the isolation is very difficult for her.

The community attracts all types of people with the illness.

I am very much a loner, but still need others, and especially now need other "believers".

I'm quiet, but not an introvert, and happiest when I have some regular interaction with people.

Travel can be difficult

Travel difficulties cropped up in some of the queries:

... my friend has cerebral palsy and needs a medical attendant ... to get him out of bed and cleaned/dressed in the morning, then conversely into bed at night. When I tried to find a home health care attendant for the cabin we'd stay in around Green Bank [an EHS community in West Virginia], there was no one closer than an hour away (and the nurse didn't want to travel that far either).

The vast majority who wanted to come were planning ahead. This one wasn't:

I have been wanting to visit your property for over a year. I am wifi, cell phone tower and emf sensitive and on vacation until the 5th [sent on the 3rd]. Would you please call me back xxx-xxx-xxxx when you get this

message as I have a variety of questions and would like to leave for Snowflake today or early tomorrow.

Asking for information

There is a lot of self-help information available online, so there were few emails asking for information. But there were some:

... But I am writing to ask for advice on personal care products. I am down to baking soda for just about everything.

Someone desperate to get a diagnosis of his illness asked for help:

... been ill for three years, with something I cannot find a diagnosis for (according to a raft of doctors). I have investigated many different avenues since I got ill but with no luck. Someone mentioned environmental illness to me and lo and behold after some hunting around the internet, I came across you community. ... I wondered whether I might be able to visit with you, however briefly, and speak to some kind person who might be able to shed light on whether what I have is recognized by your residents ...

He did come for a visit and talked to three different people in Snowflake (including this writer), but his health problem did not seem to be MCS or EHS.

I have MCS and I found out about your community through video on Guardian. In the video ... talks about sealing the walls with foil and corn starch and I'm curious if he has more instructions on how to do this. Living in my apartment has been awful – I'd like to try to seal the walls...

Determination

It takes grit and determination to leave a familiar area and move far away in the hope of a better life.

I am a emf sufferer who now has constant pain because Verizon put up a tower next to our home. I was wondering if all of the rentals are occupied. I cannot see myself camping as I am still [not?] mobile. But, I need to move because I refuse to become a pain killer junkie.

Finances

Severe MCS and EHS is often fully disabling, but since they are not officially accepted diagnoses in the United States, it is really difficult to apply for government assistance. Many do not succeed, and are relegated to live on the charity of others.

I have MCS and have been unable to get on disability and am trying to figure out a place to live where I won't get sick every few days. ... I'm just trying to figure out how to live, and make a move to the area work, if at all possible. Anyway, any advice on how people have done this on pretty much no income and no disability help would be appreciated. I'm out of options at this point.

Two children and pregnant:

We can't live here with my disabilities, but we can't afford to eat without my husband's 2nd job...we are in a difficult place and "a rock and another hard place" and hope by some miracle that Snowflake might work out. We have 2 children and one on the way.

Recently married:

... it seems impossible that I would ever make it to Snowflake, and if I did, it seems impossible I could be anything but homeless. I'm a recently married 30 year old... My husband hardly earns enough to support himself, let alone me. ... How do impoverished people with EHS not simply wither away?

This woman from Texas reports her financial devastation:

I've always made a decent living, never unemployed, and very independent and self-sufficient. That is all gone now. I don't know how much detail to go into my journey since then but I can see why people commit suicide over this condition.

A woman in her thirties is living with her parents as she can no longer work, but "the family dynamic has become increasingly hostile," so she needs other living arrangements. Her question is:

... how those in your community that are single financially support themselves? How do they earn an income?

Someone trying to help a relative asks about financial help.

Do you have any suggestions for low-income housing or communities for her to live? Although she receives some disability, are there scholarship programs to help her? Are there any jobs that she may be able to do?

Some families pool their resources to help the sick:

I'm also wondering if there are properties for rent and how much rent is going for these days. A bunch of us thought that maybe we could pitch in x number of dollars a month for rent, as she is unable to work.

Friends and family trying to help

Several e-mails came from friends and family trying to help the sick person. It was for parents seeking help for their child, or the children looking for a better place for their parents. Or for siblings, distant relatives or even a room mate.

I am writing on behalf of my sister, [name omitted] who has been suffering with EHS and some MCS for over 5 yrs now. She is currently staying with a friend in [city], but lives out of her car ... PLEASE – email me with any information you have regarding housing & help for my lovely 55 yr old sister who was always the healthiest one in our family.

My husband's aunt is suffering from MCS and EHS and cannot continue to live the way she has been living for over three years. (Sleeping in her car in front of her mother's house in [city] Her family thinks that she is crazy and won't help her. So, she's reached out to me as a last resort, I guess.

My brother lives in Phoenix and has MCS. I'm looking for a support network or someone to talk to about how we can assist him.

My name is [name] and I am looking for somewhere safe for my mother to put a chemically-sensitive trailer. She currently lives in her car but my husband and I are working on getting a custom safe trailer built for her.

Even a roommate is trying to help, or perhaps offload the trouble:

My roommate [name] has recently developed serve [sic] MCS since Jan. ... So I found this website and thought I would encourage my roommate to go to AZ to discover her own identity and learn to accept MCS as part of her life.

Openings are scarce, especially for rentals where it usually takes years to get in. That can be a rude awakening for the desperate.

... anyways [name] would like to move down to your Community in Snowflake area later this wk. [name], a friend will drive him down with a Uhaul trailer ... I hope you can assist them when they arrive and introduce them ,, to find shelter for [name] long term ,, or as long as he desires and you can accommodate.

We even got an e-mail from a homeless shelter:

My name is {name] and I work at [name], a homeless shelter in Vermont. We have a guest here who I think is chemical sensitive. She calls it

sensitivity disabled, but I think it's the same thing by the way she describes it. We are having a hard time keeping her comfortable at our shelter and one of our staff had heard about your community and it sounds like such a perfect fit for her.

Contacts from other countries

A handful of e-mails came from Canada, Britain, France and New Zealand. One of them actually came to visit when he needed to travel to the United States anyway.

This arrived from France:

I am MCS and here in France nobody trust me even my family, so it is very very hard to support this situation.

The media

Three different media outlets asked if they could come and film the community. One was from Germany.

The community had in the past been burned by sensationalistic journalists and was very cautious about allowing another journalist in.

The German TV journalist picked up on that:

I know – because I read on your homepage – you are cautious with giving journalists a permission [sic] to talk or even film you. But I will assure you: our aim is not to simplify any illness or tell wrong things about it.

Nice words, but unrealistic. A TV program has to grossly simplify in order to appeal to a general audience. And frequently they sensationalize to keep people's attention.

Friendly words from a journalist means nothing about how they actually portray people.

Another film outfit contacted us twice, also offering compassionate treatment:

... I'm a producer working on a documentary series for Netflix about people struggling with Multiple Chemical Sensitivity, Electromagnetic Hypersensitivity and other unexplained illnesses. I'm looking to profile a group of people who are living in an intentional community where there is care and respect taken for those with certain sensitivities ... Our intention with this documentary series is to look at these illnesses through a compassionate lens and give voice to those who are struggling to find

answers or gain the recognition/acceptance of those around them and the community at large.

Such fine words, but the reality was vastly different. Nobody from Snowflake participated, but they found seven people to participate in what was essentially a freak show with no compassion or comprehension. The participants banded together to sue Netflix and the production company for defamation.

About this article

This article is written by someone who lives in the Snowflake community and sometimes responds to contacts (but is not the main person).

E-mails sent to the official address are automatically forwarded to a community member's personal e-mail account. Further communication is then handled from there.

For two years all these initial contacts were also stored on the server for this project. They span from September 2016 to September 2018. There are more than a hundred e-mails, the printout is 66 pages long.

These e-mails are sensitive and personal information, which we did not share with outsiders. Only three of us looked at them.

In the article we made sure to remove all names and identifying details.

The exception is one media contact, which may be guessed what is about. They obviously did not accord the sick people they filmed any decent treatment and don't deserve any themselves.

More information

More personal stories at www.eiwellspring.org/facesandstories.html