

Social media reactions to a video about people with chemical and electrical sensitivities

Comments on social media show how viewers raise good questions, but also jump to conclusions and claim to see things that were not actually there. Many viewers were unable to fully understand basic concepts and often interpreted them as “inconsistent.” This demonstrates social media “group think” and the difficulty of educating the public about these illnesses.

Keywords: multiple chemical sensitivity, MCS, electrical sensitivity, chronic illness, environmental illness, media, social media, hate, group think, ableism, Snowflake Arizona, The Guardian

Two journalists from *The Guardian* visited the environmental illness community in Snowflake, Arizona, in the spring of 2016. In July a nine-minute video and a written article were posted together on their website. The video was titled “Snowflake, Arizona: where the residents are allergic to life.” The video was posted on YouTube, where it has been seen by more than 475,000 people and about seven hundred comments were made there as of September 2018. We read all comments and reprint about seventy of them here with our remarks.

Three people with severe MCS and EHS were interviewed in their homes. One woman lived in a house but had to sleep in the back of her pickup truck. The two others both said they were engineers and had built their own houses using special non-toxic building methods. One man shows how he deals with sensitivities to ink fumes by using a reading box for books and offgassing photocopies by hanging them up while wearing a respirator. The other man talks about their building methods, including sealing the walls with aluminum foil. He is also shown with some electronic project he is working on.

With the woman, the footage focuses on her sleeping in her truck, working on detoxing a new sleeping bag and her hopes for building a safe house to live in.

The psychology angle

At the start of the video, these two texts filled the screen:

They claim that fragrances, chemicals, Wi-Fi and other environmental factors severely damage their health.

and

Yet few medical professionals believe that their self-diagnosis of Multiple Chemical Sensitivities and Environmental Illness is real.

The intent of that message is very clear.

After repeated complaints, *The Guardian* editor agreed to remove the word “self-diagnosed,” since the three people featured in the video had actually been diagnosed by physicians. Claiming that people are self-diagnosed is derogatory. *The Guardian* resisted correcting it, but eventually relented.

Each of the three people in the video were asked whether their illness could be psychosomatic. All three did not think so; one stated “get your head out of your ass.”

Their answers were actually more thoughtful than shown, but that was edited out.

How viewers responded to the video

The video was nine minutes long. It was made to be entertaining and not educational. It left a lot of things unexplained and suggested the Snowflake people were mentally sick. Viewers were given little actual information and had to fill in several blanks on their own.

The hundreds of comments on YouTube provide insight to how the viewers identified and filled in some of these gaps. Many were unable to use the information they were given to arrive at the logical and reasonable explanation. Instead they tended to rely on their own experiences, biases and plain guesses. Many commenters spoke with great confidence about things they couldn't possibly know.

Some viewers pointed out genuine logical errors in how the video was made. Some made up things they claimed to see or hear, but which weren't actually shown and not true. Other people perpetuated these false observations. This is how false rumors start.

There were also a lot of general comments. Many were dismissive of the legitimacy of the sick people, some were even quite tribalistic. There were also

some sympathetic comments, mostly from people referencing their own experiences with these illnesses. Some comments were actually quite funny.

There were a few disturbing comments, especially by a teenager about his own dad.

Some commenters slung insults at each other, with accusations of illiteracy, liberalism, assorted mental illnesses, etc.

There was no moderator to clarify issues or remove inappropriate postings, and no simple way for viewers to flag hateful comments. The comments were basically anonymous, so people could say what they wouldn't say in person. None of the people involved in the video (journalist or "cast") made any postings.

The vast majority of the comments were just one or two lines. We've included several examples, which we show indented with spelling and grammatical errors intact.

The sensitivity to printed matters

By far the most comments revolved around two scenes where we first saw a man using a reading box to read a book and then hang up photocopies to air them out while he wore a respirator. In the reading box scene, we also saw a calendar and some photos hanging on the wall. The paper hanging scene was followed by one where he is asked a question while standing before the hanging paper, without the respirator. One viewer commented:

hangs printed documents with mask. proceeds to stand 3 feet away from said documents in the same room without mask.

This is good logic, which the journalist should have caught and provided an explanation for. What happened is that the hanging scene was staged, using copies that had already been aired out. The journalist was fully aware of this.

That part of the interview was done in an open door, with the journalist standing outside the building. It made for a good background, but an error in the logic. Sloppy craftsmanship.

Reads a book in a box because of ink fumes but perfectly happy to hang print outs of his emails up round the house.

4 *Snowflake video*

Another seemingly good observation. The offgassing room is actually a separate building and not a part of the house, but the viewers are not aware of that, as it is not shown in the video.

He said he can't touch the book but then has a calendar on the wall behind him

He didn't say that. In rare cases people can be that sensitive, but not him. The "can't touch" idea may be a misunderstanding of the reading box, which is sealed to keep in fumes, hence the hands can't reach in to flip the pages.

The calendar on the wall is a good observation. Perhaps the journalist wondered too, since the calendar briefly fills the screen, but she never asked him about it.

The reason the calendar is fine is that it has been offgassed. That particular type of glossy print is more toxic than photocopies, so every year he buys a calendar in September and offgasses it for at least 13 weeks — one week for each open spread. That particular year the offgassing wasn't quite good enough, so the calendar's picture is also sealed airtight with offgassed cling wrap, which can be seen in the video if one looks closely. Oddly enough, it is not clearly shown, though it easily could have been. Again, no actual inconsistency, but the video makes it look like it.

He has a calendar and pictures on his wall, what does he think they're printed with?

The pictures were, of course, also well offgassed before they were hung on the wall. He reports that some types of photo paper offgas much faster than others, and some never become inert.

Can't touch a book but can photo copies, what a load of bollox, so many contradictions in this!

Someone else picked up on the "can't touch" misunderstanding and took it to the logical conclusion — except on a false premise.

Steen has to wear gloves and use pencils to read books because the ink and paper give him problems.

He doesn't wear gloves, and doesn't need to. It's purely an inhalant problem.

And why does he use more protection with a book that has dried ink than with freshly printed copies (which really do often smell strong enough to give me headaches)? It's not that I doubt him, it's the weird inconsistencies.

This statement is the only one giving anyone the benefit of doubt. It would take too long to offgas a book, page by page. The ink in books doesn't offgas because the pages are sealed against each other and not exposed to the air, so they do not really air out for many years.

It's toner particles that have been baked into the paper, while all other particles that were not successfully baked were removed via electrostatic pickup and disposed within the printer. There is no way he could have any particulate or toner floating around him — this guy is just crazy.

The toner offgasses toxic chemical fumes even after it is baked onto the paper. Many people can smell a fresh photocopy, not just those sensitized to the fumes.

how can dry ink smell?

Some people really can't smell a fresh photocopy, apparently. They probably can't smell fresh paint either.

The guy is reading a book, an old one that would have been totally out-gassed a decade ago and the book is in a new petro-chemical plastic box . . .

The book wasn't old at all, and the plastic box was several years old. This viewer made up two falsehoods on his own, as none of this is discussed in the video. Other commenters picked up on the "old book" idea, and it gets older and older as people keep referring to it. Eventually it is said to be 30 years old!

Sleeping in a pickup truck

Several commenters thought that sleeping in the back of a pickup truck did not make sense. It is certainly not perfect, but it is actually better than many alternatives when a custom-built house is not available.

These people just aren't consistent. That lady dislikes waterproof smell, but she lives in an old pickup where the clear coat is probably wearing off.

um dude the woman sleeps in a painted car next to a gas tank

Chemicals in sleeping bags are bad but gasoline is ok.

Car paint is extremely toxic when applied and several months after, but once it is fully cured and offgassed it has a hard surface and is much more inert than most types of wall paint — including most “natural” paints.

Car interiors are toxic for many years, but she sleeps in the back of the pickup truck with a custom built all-aluminum cap on top and no plastic bed liner. She is well away from the engine, which she keeps very clean so there is no oil smell. She also makes sure there are no gasoline spills. The gas tank is well sealed, as it is on all modern cars. There are no gas fumes where she sleeps.

What is he hiding?

The first guy was asked what he does with this time. He answers that he spends about two hours a day reading. When asked what else he does, he evades the answer. This results in some commenters speculating what he did, a discussion that is not printable.

Asked about what really happened, he told this writer that he couldn't think of what to say, other than a personal project he was busy working on at the time but he didn't want on television. He did explain it to the journalist with the camera off, but they chose to show the seeming evasion anyway. The journalist taped many hours of footage and used so little, why use this one instead of the more educational parts left out? That was definitely not a friendly move.

It is not easy to be in front of a camera. They don't give you second takes. The Snowflake people are not professional talking heads who are experts at presenting a perfect image. Besides, many people with these illnesses have cognitive difficulties that make it harder to “think on your feet.”

The foiled walls

Some commenters were puzzled by the foiled walls, which were actually explained in the video.

Their tinfoil wrapped walls don't do shit to keep out the HF to UHF waves. They might radiate heat away, a little, but that place is 100% filled with all kinds of radio waves going all around them and the guy isn't bothered by that.

Actually, aluminum walls have been tested to shield UHF radio waves by a factor of 100 to 1000. And these houses are in a low-radiation area well out of town. The radiation inside these houses has been measured and is about 10,000 times lower than on a typical street in a city.

The main reason for the foiled walls did occur to just one commenter:

I think they're actually using the metal foil as a barrier to seal in smells coming from walls and things.

The graphic description of how well the foil seals was apparently a little much:

Yea the man says you could poop in aluminum foil and wrap it up and nobody could smell it like a **TOTALLY NORMAL PERSON.**

Miscellaneous other perceived inconsistencies

There were other things shown in the video that needed some explaining.

He can put a chemically made gas mask on but old dry ink fumes (yea, right.)

That is a valid question. He actually offgasses new respirator masks for at least two years before using them.

he's having lights to turn on, but a non-analogue video camera with a lower net impact emf [emission] than a single light switch in his house and he is having invisible five year old squabbling in his psyche.

The video doesn't at all mention the specially designed electrical system in the house, which uses pure, clean, transient-free DC electricity. Even with the regular grid power, the high frequency emissions from portable electronics, such as a video camera, can be more troublesome when close to it.

The “five year old” was an attempt to explain how the radiation can affect the brain, but it is hard to explain to others, just as it would be hard to describe a migraine to someone who has never had one or what autism is like.

Lots of inconsistencies with these people. I also noticed the woman who lives in her van uses plastic bags to store things. I thought plastic “off gassed” nasty chemicals too.

Of course, she offgasses her plastic bags on the clothesline before using them. Some types of plastic are also much safer than others. And she sleeps in a truck, not a van.

How many of these nuts have fillings in their teeth? Do they think they are breathing different air than the rest of the planet?

Like most people with MCS, the three people in the video have had all mercury amalgams removed.

The sun produces as much radiation as the technology they are trying to get away from.

Not by a very long shot. The typical city person is irradiated by microwaves millions of times stronger than what comes from the sun. Besides, many people with electrical sensitivities do have problems with sunlight too. Hence one of the men uses a wide-brimmed hat and very dark sunglasses.

To me it seems his “allergies” are tailored to keep him from whatever can stress him — newspapers, technologies, modern life.

Then why does he go to the trouble of offgassing so much stuff and pay people to manage his emails? But this illustrates how limited this video is, since we don’t hear about all the other things he is reactive to. An example of viewers believing they’ve seen a comprehensive description.

The Chuck McGill factor

Several commenters remarked that the Snowflake people were similar to the fictional Chuck McGill character on the television show *Better Call Saul*. The show depicts Chuck as mentally ill, especially in the third season, which aired in 2017. This TV show probably created some stereotypes about people with EHS.

Someone needs to tell these people Better call Saul is just a TV show.

They are all real life chuck mcgills

Must be liberals

Some viewers seem to think people with such an illness must be liberals, even though none of the people in the video made any political statements.

Anyone else notice the majority of them are liberals or people with British accents?

And they all voted for Hillary.

They all seem to be from the very privileged culture that gave them the tools with which to manipulate others. Painful to think of all the healthy natives that were cleared off this land to make room for these prizes of selfishness.

I'm happy there are no voting booths out there.

The location

The nearest town is named Snowflake after Mr. Snow and Mr. Flake, two Mormon pioneers. Some commenters find that amusing, as the term "snowflake" is used as a slur on Millennials who are highly sensitive. The combined wisdom of the commenters produces gems like:

Should be called fruitloop, az

EVERYONE is Mormon . . . This is a scam of some kind

A democrat's paradise

I wish more people like that would move to the middle of nowhere.

So basically there is a chunk of desert heavily populated by morons. Sweet.

Town of lunatics. At least they group together away from everyone else in isolation. I would hate to live near someone like that.

In actuality only one family in the environmental community are members of the Mormon church. The area is socially and politically very conservative; in the 2018 election the Republicans won 85% of the local vote.

Hateful comments

There was a very large number of hateful comments, such as these:

I honestly just think they're all batshit crazy and are living off welfare

Hypochondriacs

Great community of schizophrenics, at least they can bulk buy on tinfoil. Why do all of them make tinfoil scout hats, they should style them up make a baseball hat.

No tinfoil hats displayed or used by the three people in the video — or anyone else in the community.

I hope we can all just appreciate the difference between air quality and “I need to be in a smell controlled hyper bubble because I refuse to tolerate odors”.

Theses [sic] are fucked in the head. They really seem to be enjoying this stupid way of living.

Look they need to be on television, otherwise their “sensitivities” will go away.

Sounds like another form of OCD where the individuals have to perform some type of act to prevent or alleviate what they perceive as noxious chemical threats in order to feel like they have control over their lives.

Normally you have one village idiot. This is the whole village of idiots.

whatever gets you off the grid. They lying about why they are like this. Social misfits.

I thought I had seen it all . . . I was obviously wrong! I think they do this just because they want to be noticed . . . here's hoping these people do not ever procreate . . .

I was expecting more Millennials

I can understand dust allergies, but this is just insane.

What a bunch of whack jobs. Hope they don't start breeding with each other.

The most disturbing thread

A teenager posted about his dad, who is electrically sensitive, which really annoys him since he is not able to have Wi-Fi and the family can't go visit family, etc. He states, in part:

It's funny to watch these people until you have someone in your life who is as crazy as them. . . . Luckily next year i'm off to college.

Things like this is hard to live with but not for them, for the people around them.

A commenter suggests placing a Wi-Fi router or a flat computer screen under the dad's bed. The teenager responds back that won't work because dad uses two meters to check daily and sometimes even wakes the boy up at night when he can measure radiation coming from the boy's room.

That is a family with serious tensions and a kid that doesn't support his dad.

Supportive voices

There were several supportive voices as well. They just seem to drown in all the negative comments.

Yes it is real. I didn't spend the end of last year and beginning of this year in ICU due to a mental illness. Acute respiratory failure. . . Once landed in the hospital from a woman dipped in perfume getting

on an elevator I was in. She was a pharmaceutical rep. It would be funny if it wasn't deadly.

My grandmother was actually allergic to smell of ink in newspapers.

My mother became hyper sensitive to smells and light . . . I have been a nurse for 40 years and I did not understand . . . I have spent the years since her death studying the latest info . . . I wish that I had known this info then so that I could have had much more compassion.

They complain less than the average individual. The average individual doesn't have much to complain about.

I can believe it's real. They're giving up way too much to live the way they do now.

I've just retired after 25 years as an indoor air quality specialist for a school district. For some people, this is a very serious condition.

My heart goes out to these people. Yes, they ARE the 'warning signal' of how we have polluted our world with mass technology.

This show is offensive to those with MCS. So you can accept that severe asthma, severe contact allergies exist so much that schools ban peanuts and have epi pens and defibrillators . . . but not that some adults have multiple severe chemical sensitivities that cause them to retreat from society?

Unfortunately the way the interviews were edited did present this community as rather awkward. There is nothing wrong with their minds. Their suffering is REAL.

Because social convention tells you they look crazy. To them you look like a basket case.

Those lacking compassion and/or empathy should take a look at themselves . . . one pointed finger means three pointing back @ the one judging.

I want to go there

Surprisingly, two viewers seemed drawn to the Snowflake community:

I want to go there and love in a tiny cottage. They seem nutty but nicrm [sic]

I want to chill with some of these folks.

Offering help

A few folks offered their advice, though nobody suggested asking the sick people what they actually needed.

THESE creatures are very very sick in the head! THEY need to see a psychiatrist and take all kinds of medication. THESE things are not normal. God help them.

cell phones causing cognitive decline due to radiation is a real thing but it can easily be fixed with activated charcoal or Organic Germanium-132.

Praying, Listening, Organic Cilantro, (coriander plant greens) wild Seaweeds, tested spring water, juicing fresh garden greens and carrots, wild herbs, teas . . . lemons . . . ginger, turmeric . . . cucumbers, parsley . . .

They need JESUS

. . . they're hurting themselves, and its kinda fucked up to not help someone who needs it. Sure, a heroine junkie isn't hurting anyone else, that doesn't mean we should turn our backs on all junkies.

These people should get actual help, not move to the middle of nowhere to live in delusion.

Final solutions

Some commenters suggested more radical solutions:

This is Viper 1-7, target in sight, commencing bombing run now.
Two away

and

I watched 2 minutes of this video and quickly realized these people don't deserve to live. Major mental problems. BYE BYE
Problem eliminated

What can be learned from this

It is clear that many people have great difficulty comprehending the lifestyle imposed on hypersensitive people. It is so different from their own daily lives that they can't apply what seems to be logical explanations, such as if there is a calendar on a wall, and we see him offgassing paper, then it should make sense that the calendar is offgassed too.

When producing a film about people with these extreme environmental sensitivities it is essential to identify and cover such gaps. Otherwise people fill them in themselves and rarely with the correct answers. The gaps are fuel for sinister explanations and rumors. Other people may find these faux explanations believable and thus accept the conclusions that the sick people are inconsistent and thus not believable. The "wisdom of crowds" does not seem to work here.

This really demonstrates how attention to details and explanations are needed when producing such programs. They really need someone with specialist knowledge to be a part of the editing team. Producers and editors without specialist knowledge would be just as likely to make similar incorrect assumptions as the general audience, as it apparently happened here. However, this writer could not have foreseen all the many misinterpretations!

A fundamental problem is that commercial need gets in the way. Entertainment sells, while educational programming struggles to break even. Documentaries have to be made entertaining to sell and that limits their educational value.

Another fundamental problem is that viewers tend to think that such a nine-minute video gives them a comprehensive coverage of such a complex subject. There is actually very little information in this video.

The seven hundred commenters represent about 0.15% of the total viewers. The question is whether they are representative, or just a vocal and largely intolerant, opinionated and uninformed minority. What did the other 99.8% think when they

saw this video? How many read the comments and how did that shape their perception?

The making of the video

The video was made by Mae Ryan who flew in from *The Guardian*'s office in New York. When she originally contacted the community for the interview, she was asked whether she intended to also interview a physician. When she – very reluctantly – admitted that, the interview was declined. Having a psychiatrist state that the illness was all in their heads would refute everything the three people said in the minds of most viewers, unless there was also a physician supporting the sick people. No balancing physician was planned or offered.

The journalist later contacted the community again and asked for an interview if no physician were interviewed. This was accepted. This agreement was not mentioned in the video, but it was in the written article and not at all positively.

The filming took place over three days, where the two journalists hung around their host's home, or they visited the homes of the two other people featured. Hours of footage were made, which was edited down to the nine minutes actually shown. It is in the editing process that the journalist shapes the message of the video, deciding what to show and what not to show of the interviews, etc.

The two journalists were each given a small stack of articles from scientific journals supporting the illnesses as legitimate and not psychosomatic. That did not seem to make much of a difference. Did they even read any of it?

The three people in the video were not paid for their efforts. They all did it in the hope that it might raise awareness and acceptance, and trusted *The Guardian* to be on the side of the voiceless, as they claim they are.

The written article

The written article was made by the other journalist, who interviewed the three people in the video and a fourth person. She chose to write about just two people, including one who was not featured in the video.

The article was very negative. It appears that the journalist was bit of a princess, as she bitterly complained about the accommodations, which were not up to her standards. She also talked a lot about her own mental illness, including her stay at

a mental hospital two years before. She projected her own problems onto the people she interviewed, apparently assuming they had the same illness she had.

The article also had various factual errors and interpretations.

It was basically character assassination. Since *The Guardian* claims that they “give a voice to the voiceless, challenge the powerful and hold them to account” it is surprising that they published it.

None of the comments to the video mention the article, so it may not have been an influence. They are different media after all, and the YouTube entry did not include a link to the article.

About the author

This writer has had MCS and EHS for about two decades, has known the three people in the video for many years and seen their living situations many times.

More information

Other articles about media impact on the environmental sensitivity community are available on www.eiwellspring.org/media.html.