

## Talking to the media about environmental illness (MCS or EHS)



What to expect if agreeing to an interview, what to look out for and how to negotiate some ground rules and accommodations.

*Keywords: journalist, media, TV, magazine, video, documentary, interview, how to, participate, chemical sensitivity, MCS, electrical sensitivity, chronic illness, accommodation*

### **Why talk to the media?**

The picture above is from a visit by KBSTV from South Korea. They are interviewing two young women, who are camping in a station wagon.

Media stories can reach many people who would otherwise not hear about MCS or EHS. This can help people who have these illnesses, but have not been diagnosed, start asking better questions and perhaps find the right kind of physician to diagnose and help them. It may save some people from years of suffering and inappropriate treatment.

A media story can also help us get more accepted. It is much easier to ask to be accommodated in a store, a medical facility or at work when people have already heard about us. It may also help get funding for medical research to find out why we get sick and how to treat the illness — research is sorely lacking due to very little funding available. Funding of research is very much influenced by public opinion.

On the other hand, a negative media story can damage our cause. Some journalists have been hostile towards us and produced stories that painted us as having an imagined illness and the doctors who try to help us as quacks. Such stories create stereotypes about all people with these illnesses.

Stories that are sensational are also not helpful, since it is difficult for readers and viewers to relate to the people in the story.

I have been interviewed by two TV stations, two radio stations, one print magazine and one online magazine (which did both a video report and a written story). I also know four other people who have been interviewed.

Most of the interviews I participated in were positive, but I have been rather careful in who I talked to and what I said. I know people who have been less fortunate and really got burned.

### **What the media wants**

There are two types of media: public and commercial. This is an important difference.

Commercial media dominates in America, while public ownership dominates television and radio in Europe and many other places.

The commercial media needs to sell advertising to exist and needs to keep people captive. They are therefore more likely to distort the real story in order to make it more sensational or to emphasize controversies and conflicts as that, unfortunately, appeals to a lot of people.

Public media, such as PBS and NPR in the United States and BBC in Britain, are much less likely to be sensational.

Some media have a political agenda that influences how they report each story. A media that supports a right-wing agenda is unlikely to be sympathetic to people harmed by industrial pollution. However, mainstream and liberal media have produced some awful stories as well.

Commercial media also have to be mindful of not annoying potential advertisers. Just see how long it took for the mainstream press in the United States to talk about climate change and how little they criticize the pharmaceutical industry.

### **It will be simplistic**

All media need to simplify a story to make it easy to understand and brief enough that people do not lose interest. This is difficult to do for a complex issue such as environmental illness. They tend to pick a few obvious things to highlight and ignore the rest. If the person they interview has both MCS and EHS, they tend to just mention one or the other. If they use still pictures or video, they will tend to go with what is visual, such as respirators, aluminum-foiled walls, RF meters and reading boxes.

Commercial video and television tend to condense and simplify their stories more than public television.

It is highly unlikely that they will show you making a lengthy statement or quote you at length. They may let you make such a statement, but it will be cut down to a sound bite or left out entirely.

A TV crew can spend a full day with you, but the end result may be just a few minutes of video. A journalist may spend multiple days on a visit and call it “in-depth reporting,” but it is really still quite superficial.

### **How people react**

Despite the simplistic result, the readers/viewers will tend to think that they have been fully informed on the issue. This is especially the case with video and television, which are such powerful media that makes people feel they’ve “seen it with their own eyes.” It is easy to manipulate an audience because of that.

It is revealing to read people’s comments on media websites — how they make judgments based on what is really very limited information. One example was an article about people who were electrically sensitive. The article mentioned riding in a car owned by a sensitive person. A commenter thought that was proof people with EHS were faking it, since cars radiate EMF. The journalist was told about the various low-EMF vehicles, but she didn’t mention it in her article. It was probably too technical.

In a magazine video we see a man using a reading box to protect him against the fumes from a book. A colorful calendar hangs on the wall behind him, which many social

media commenters thought “proved” that his sensitivity was not real. They had not been told he had spent three months offgassing the calendar, page by page.

### **Talk to the journalist in advance**

If at all possible, talk to the journalist before you agree to an interview. You have the right not to agree to be interviewed. Even if you’ve already said “yes” you can still change your mind once you learn more. You are not obligated.

But if you say “no,” do it before the journalist travels to your house. An angry journalist may decide to write the story anyway, and you can be sure it won’t be a friendly one.

You can negotiate some conditions for the interview during the pre-interview conversation. This can be accommodations to keep you safe and it can be about the article itself. Be careful here, as your requests can backfire. These issues will be covered later on.

Journalists are busy people. They do not have much time to work on each piece so they are unlikely to read a book or any medical articles you may send them.

### **Find out what angle will be used for the story**

The journalist usually has a specific angle in mind for the story. Sometimes he or she is willing to talk about it up front, if asked. This can be very helpful for deciding whether to participate or not.

I was once contacted by a South American TV station that was producing a series called “Fantastico.” Obviously sensationalistic, so I declined. Another TV station was making a series about neighborhoods in conflict or “on the edge.” I declined that also. Tabloid magazines or TV programs are rarely a good way to educate people.

A journalist who plans on making a scathing story surely won’t say so. They know that will not get them the interview. Instead, they may say something like “I’ll just report as it is” or a similar vague statement. The people who signed up for the 2018 Netflix series *Afflicted* were told it would portray them through a “compassionate lens,” but that apparently has different meanings to different people. Some journalists may not really know in advance how they will slant the story, but I think the vast majority know.

If the journalist says she knows someone with MCS or EHS already, that raises the odds of a sympathetic story. But it is not a given; I know a case where the resulting story was

rather neutral, though it did label people as “self-diagnosed” (even though all had been diagnosed by physicians) and other details that cast doubt that MCS was a “real” illness.

### **Are they interviewing any doctors?**

Ask ahead of the interview whether they will also interview any doctors. Many stories about us feature a physician who says MCS or EHS is just an imagined illness. Journalists consider that a balanced story, since both sides have been heard. It is not balanced since a physician, filmed in a white lab coat and in a clinical setting, commands a lot more respect.

Ask about this directly. If you get a vague answer, ask again until you get either a “yes” or a “no.”

I have a friend who considered an interview, but declined when the journalist admitted (very reluctantly) that she also intended to interview a physician. The journalist later called again and said she was willing to drop the interview with the physician. My friend then agreed to the interview, but the article prominently told the readers that this interview was done on the condition that the journalist didn’t talk to any psychiatrist. A lot of commenters found that to be the most damaging part of a very negative article.

A better approach may be to make it a condition that if there will be any physician, there will have to be two — one for each side. And they must be given equal time and treatment. Of course, clever editing can still make both doctors seem to agree that you are nuts.

You can suggest they interview a doctor who treats you, or you can ask them to contact the American Academy of Environmental Medicine for a referral. Or ask a support group for a referral.

This two-or-none approach has not been tried yet.

### **Other conditions**

I just read a story about an immigrant community fighting pollution of their drinking water. The journalist wrote that the interview was granted on the condition that the article did not emphasize the poverty there.

You can make such conditions, if they are reasonable and you don’t mind the journalist mentioning the condition in general terms. You can’t demand that the article will be sympathetic towards you, but you can ask that the names of your children are not

mentioned (a common request), or where you work (worked) or other things that are obvious to a visitor but you find are too private or may complicate legal proceedings (such as related to your illness).

Videos will usually display your name on the screen. You can ask them to use your first name only; they will probably insist of some name to be displayed.

A print journalist is unlikely to grant you anonymity, or just use your first name, unless there is a compelling reason such as your safety.

### **Check the journalist's work ahead of the interview**

A lot can be learned about the journalist and the media he or she works for by looking at previous articles and videos they publish on the web. Everybody has their own style and what you see there is likely how they will treat your story as well.

Do they tend to stick up for the little guy against corporate interests? Do they treat everybody with respect? Do they emphasize controversy and confrontations?

Some media are just unlikely to be sympathetic. I've once flatly refused to talk to Fox News. A friend refused to talk to ABC Nightline, since they've aired multiple negative programs about MCS, including one about Dr. William Rea.

Some media tend to stick up for the little guy, but can still bring an awful story. I've seen that happen with the *Guardian* and the *New Yorker*. There can also be pleasant surprises, such as *Popular Science* bringing a very respectful article about someone with extreme electrical sensitivities.

It is important to check up on the individual journalist, too. One wrote a very scathing story about two friends of mine. When we googled her name we found some disturbing stories she had previously written about other people. Don't skip such a simple checkup, no matter how friendly the journalist appears to be.

### **Accommodations**

If you have severe MCS or EHS it is best you ask for some accommodation. You need to be clearheaded in order to present well. The journalists will not know how you are normally. If exposures make your speech slurred, your personality confrontational or your intelligence twenty IQ points lower, they will think that is normal for you.

A common request by people with MCS is to be interviewed outside and ask the journalist to refrain from using any scented products. This does not make them safe, but it all helps.

If possible, schedule the visit for a time when the weather is likely to be good for an outdoor interview.



*A video journalist and a print journalist, who helped holding the microphone.  
Notice the wire to the mic.*

In two cases the journalists agreed to a more elaborate cleanup, including showers and borrowed clothes and not staying at a motel or renting a car. It went well in the first case,

but in the second case the journalist was a bit of a princess and she focused her whole story on these things, in a way that was way out of proportion to the actual events.

An elaborate cleanup is too far outside most journalists' comfort zone and is not a good idea. If you can't make do with the journalist minimizing the use of scented products and doing the interview outdoors, then it is best to decline the interview. A full immersion in the EI lifestyle is too big a culture shock.

People with EHS can request a *wired* microphone, as most mics are wireless today. The video journalist may need to bring a tripod to hold the microphone.

You can also ask the video journalist to use a longer lens than normal, so the camera (and the journalist) can be a little further away during the interview. This may require a separate microphone.

You will need to discuss all these things before the journalist arrives, so he or she can make the necessary preparations.

### **The journalist will be friendly**

All journalists know that it is a lot easier to get people to open up and talk freely if there is a friendly rapport. Every interaction I've had with the media has been very friendly and easygoing when they visited. That does not mean they are your friend, some of them are not. I've been interviewed by a very cute journalist who interviewed five people and then wrote a knife-in-the-back story on two of the other people.

### **Beware of the culture gap**

Every minute you spend with the journalist is, in fact, part of the interview. Everything they see and learn will shape their story. Remember, what we have to live with every day is hard to comprehend for outsiders, including journalists.

There is a big cultural gap between people with serious disabilities and the rest of society. People who are able-bodied cannot really relate to what it actually means to have a disability. They may somewhat understand what it means to use a wheelchair, but only somewhat, as that is more complicated than it looks. With invisible disabilities, such as environmental illness or migraines, it is much harder for the journalist and the readers or viewers to relate and comprehend the impact. They will not really understand what it is like to be treated with suspicion, and sometimes outright dismissal, by old-school physicians. Or what it is like to get brain fog every time you go into a store or run into



someone reeking of perfume. Or the many other effects we may have from what other people think of as “normal life.”

It is hard enough for our friends and families to comprehend the illness, and they have much more time to learn than a journalist, so don't expect a journalist to really understand it.

Many journalists try to be neutral, but they will always be influenced by their own life experiences. We all have our biases and so do they. Besides, as death-camp survivor Elie Wiesel said in his acceptance speech for his Nobel Peace Prize: “Neutrality helps the oppressor, never the victim.”

When you talk about your illness, try to describe what it is like to you, what it does to you, rather than just saying that pesticides or mobile phones are bad things — most people voluntarily pay money for those things.

### **Avoid controversy**

There is a limit to how much journalists and their viewers and readers can accept of new material. MCS and EHS are plenty controversial by themselves — adding more controversies will just create an overload and erode credibility.

Avoid discussing politics, alternative treatments, conspiracies, chemtrails and other things that are not generally accepted. Also avoid making sweeping statements about the causes of MCS and EHS. There are no established facts on any of these issues, even though some people have strong opinions.

People who read or view the story will stereotype what they see to apply to all of us, just as people stereotype women or people from other cultures, races or religions.

You can discuss controversial things off the record (make sure all recording devices are turned off), but consider whether it really benefits anything. I know one case where a person with MCS shared her pet theory about a way to diagnose MCS. Even though she spoke off the record, this scientifically unsupported idea made it into the article anyway. It was just mentioned indirectly and not at all positively.

### **Avoid talking about alternative treatments**

To most people, alternative treatments beyond a handful of vitamins look weird. Most people, and journalists, don't understand that mainstream medicine has little to offer people with chronic illnesses so their choice is to try alternative type treatments or do

nothing. Until about twenty years ago that was the situation for people with AIDS and cancer too, until medical science improved, but many don't know that. (See the film *Dallas Buyers Club* as an example.) It is simply best to not discuss alternative treatments, no matter how hopeful you are about the latest thing you are trying.

For an example of a TV program with lots of alternative treatments, watch the 2018 Netflix series *Afflicted*. It did not come out positively.

### **Respecting your privacy**

Some journalists do not respect privacy. They seem to think that when you agree to an interview, everything is fair game. It isn't, but they have the power of the final word.

In one video interview they asked an intrusive question. The man responded reasonably "I don't want to talk about that," which was used in the video to make it look like he was hiding something. I suppose a better response would have been total silence, but a hostile journalist can always manipulate things.

### **Beware of baiting**

During one interview with me, the journalist abruptly changed the subject with the question "Is there a war going on?" It was clearly meant to catch me off guard and say something strongly worded. Luckily I sensed I needed to be careful, so I just said "No there isn't a war going on." I didn't have time to think of a better answer, but that was certainly better than any sort of tirade about industry shenanigans. It would not have looked good on TV.

### **Avoid "theatricals"**

Some of the early TV programs featured people who deliberately exposed themselves to the point where they had seizures and rolled around on the floor. Those demonstrations are dangerous and I don't think they garner much sympathy from a TV audience, anyway. They will not convince many people that environmental illness is a legitimate disease. Don't do this to yourself.

### **Prepare yourself**

It is difficult for many of us to come up with good answers on the spot. It can be helpful to think of general questions you may be asked and what to reply.

You may be asked about the controversy around your illness, and that some people think it's just imagined.

Or there may be a question of what you think about the companies selling toxic chemicals and wireless devices.

Don't try to memorize an answer, but think of some reasonable points to make on such topics. Professional spokespersons, politicians, etc. do this all the time.

Remember, you are a sort of ambassador for everybody with the same illness.

## **Documentaries**

Documentaries are films and TV programs where real people are filmed instead of actors. Viewers believe such programs to be authentic, since they see what real people say and do.

Be as careful participating in one of those as with any other media form. They can be just as biased, and their impact can be large because they seem so believable. The producers can edit the raw footage, add banners with statements and include people you don't even know to promote whatever message they want. For an example of these methods, see the 2018 Netflix series *Afflicted*.

Ask them for a list of their advisors, then check up on who they are and what sort of expertise they claim to have. Also look at some of their publications. If the film crew does not have any advisor, that is a bad sign, especially if it is a well-funded outfit. If it's a one-person crew (like it was for *The Sensitives*) then it may be okay, if the person genuinely wants to spend the effort and time to learn about us.

## **You won't see the result before publication**

The journalist will probably not send you the article or video before it is published. They may call or e-mail with a question, but you do not get to approve anything.

All popular media are subjective. The journalist simply reports his or her subjective perception of the matter, based on his or her personal biases. To them, that is as good as your opinions.

## **Complaining about a story**

You can complain about a story, if you think it is too biased or inaccurate. You can try contacting the journalist, but it is far more effective to complain to the editor. Public television stations often have an independent board to handle such complaints.

Some mainstream media take such complaints seriously, if you can point out specific factual errors. Some media do not care if they are wrong or unethical (just look at the tabloids).

Public television stations usually have a requirement to be factual (with a lot of leeway). Private TV stations may not. Two TV journalists once sued a Fox News affiliate they worked for over that issue. They lost.

It is very unlikely that a story or program will be pulled off entirely. They may agree to edit or remove parts of the text in the article or shown on the screen (I have been able to do both).

The first time you contact them, you may be brushed off. Try again. Be polite and be factual, that will get you further.

### **Should you participate?**

Be clear with yourself why you would like to participate. Also be clear if you can live with whatever the journalist creates about you, even if it is quite negative.

Also be clear whether other members of your family should be interviewed. If your spouse is likely to be critical of you, it's best to avoid that possibility entirely.

Being filmed is a lot harder than talking to a print journalist. Don't agree to it if you can't look calm and presentable in the eyes of a mainstream audience. They will not comprehend that you're having a bad moment.

And make sure to check these points already mentioned:

- prior work respectful and not sensational?
- doctors also interviewed?
- what is the angle?
- negotiate accommodations
  - not wear fragrances
  - interview outdoors
  - no wireless microphone
  - longer lens on video camera

## **Case study: Biosphere 2**

The tactics and limitations of the press was on full display during the Biosphere 2 experiment, where eight people sealed themselves up in a closed environment for two years. The project received a lot of media attention.

One of the eight participants, Mark Nelson, wrote the book *Pushing Our Limits*, where he tells how the media distorted and sensationalized things. There were even outright falsehoods, such as saying their miniature ocean was dying and that loads of dead fish were scooped up daily; that they washed their clothes primitively in a stream (they actually used washing machines), and kept saying the experiment was a failure.

Since the crew consisted of both men and women, parts of the media kept fishing for whether some slept with others, and even if a baby might be born inside.

## **More information**

Additional articles about media portrayal of people with environmental illnesses, and audience reactions, are available at [www.eiwellspring.org/media.html](http://www.eiwellspring.org/media.html).

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