

Oral History with Jeffrey May

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Interview of Jeffrey May

SESSION 1 (5/12/2020)

[00:00:00]

This section has been redacted in the transcript.

YIU: Okay, wonderful. I just wanted to get started by really having a basic introduction of who you are as a person. I know that you grew up in New York City. When were you born? Can you tell me a little bit about what your neighborhood looked like?

[00:05:55]

MAY: Yes. Well, I was born in 1944. It was just a suburban neighborhood. I went to public schools. I would say it was a pretty happy childhood.

YIU: Did you live with both of your parents? Do you have any siblings?

MAY: Yes, I lived with both parents and I have a brother.

YIU: Oh, I see. Is he older than you?

MAY: Yes, an older brother. He's a pharmacist.

YIU: Yes.

MAY: He lives on Long Island.

YIU: Oh, I see. What was your relationship with your brother like?

MAY: It was fine. What does this have to do with chemical sensitivity?

[00:06:54]

YIU: Yes. The reason we ask these questions is because we would really like to get to know you as a person. Some folks develop chemical sensitivity in their childhood and some folks don't. To get an understanding of who you are and how you are able to obtain emotional support or healthcare access, we ask these questions to better contextualize your life and you as a person. That's the reason that we asked these questions.

MAY: Okay, well, I mean, I feel pretty—we have a pretty good relationship. We still—we're in contact to this day. My brother—he's four years older. He loves to teach so whenever he would learn anything that excited him at school, he would teach me about it. He was interested in science. I got interested in science very early and I did a lot of experiments when I was a kid.

[00:08:06]

YIU: Oh, wow. What was the house that you were living in like when you were young?

MAY: It was a single-family home.

YIU: Yes. Your family was middle class, you would say?

MAY: Right. My parents both worked.

YIU: What did your parents do?

MAY: Well, my father started a drugstore in the 1930s, in Manhattan, and then his wife joined him. So, they both worked in the store together.

YIU: Did you remember any particular products that were used in your home to clean and—I know that, in your pre-interview, you wrote that your exposure was due to a truck, but, before that incident, did you notice any products or scent?

MAY: No, nothing. It was interesting, actually, that, as a kid growing up, I never had any kind of allergy problems at all. My brother had very bad allergies—pollen and outdoor allergies.

YIU: Interesting. But, you never had any?

MAY: Not at all, no. Zero. I would say, when I was in college, I got an apartment and we had to furnish the apartment. I had three roommates and we spent one entire day all over the five boroughs gathering furniture for the apartment. We picked up a U-Haul around six in the morning or seven in the morning—

YIU: Oh, wow.

MAY: —and we drove into every borough and we would drop things off. It was all used stuff, all used furniture that had been advertised. I think it was called the Want Ad Advertiser—I don't remember. I bought a bed that was thirty years old and it cost me five dollars.

YIU: Wow.

MAY: Ever since that day I had allergies.

YIU: Oh, my gosh, so, that bed—

MAY: Well, since I slept on that bed, anyways. Yes, it was probably riddled with dust mites, you know—it was five dollars.

[00:10:24]

YIU: How old were you?

MAY: Well, let's see. I would have been—it was my second year of college. 1963, so—nineteen.

YIU: Wow. When you were nineteen and that had happened, did you think it was weird or did you make anything of it?

MAY: No, I just figured, my brother always have allergies. Now, it was my turn. First, it was outdoor stuff. Then, probably indoors. I didn't have any testing, really, until many, many years later.

YIU: Right. When was the first time that you got tested and what test did you do?

MAY: They just did the skin-prick testing, I don't know. I guess it was, maybe, 1990 or something like that. It was dust mites and mold and tree pollen.

YIU: Right. Going back to the neighborhood that you grew up in, was it a middle-class neighborhood? Were there any—

MAY: Yes, it was middle-class. There was no exposure to anything.

YIU: Oh, wow. I know that you went to Columbia, is that right—for your undergrad?

MAY: Yes.

YIU: What was school like? Did you develop your sensitivity during going to school, or after?

[00:12:06]

MAY: Well, just the allergies, yes. But, I mean, nothing really bothered me. I majored in chemistry and I took organic chemistry. Even in graduate school, I taught in labs. There would be, like, fifty kids

boiling benzene—not even in the hood. It would be, like, fifty people boiling benzene during an experiment all into the room, and ether, and chemical solvent you could imagine. As a teaching assistant, it was the same thing—nothing really bothered me.

YIU: Right. You taught chemistry and you did your PhD at Harvard, right? Did your—

MAY: I was in the PhD program but I quit. I got a Master's.

[00:13:00]

YIU: Got you. During the school years, did your allergies or your sensitivity affect you, at all?

MAY: No, I don't think so.

YIU: When you started working, what was your first job?

MAY: I'm trying to remember. After graduate school—well, teaching, okay. The first job after teaching was teaching chemistry in a private school. I did that for seven years.

YIU: Oh, wow. What time period was that? The 1990s?

MAY: Yes, no. Let's see. Probably started about '75, maybe, to '82 or '81—something like that.

YIU: Okay, so you taught chemistry before you were driving that old Ford truck that you have mentioned?

MAY: Right, yes. The Ford truck, I bought—my wife and I bought a three-family in Cambridge and, so, yes—got all used kitchen cabinets. I got the truck to haul stuff around.

YIU: You were living in New York City at the time, or—?

MAY: No, this was in Cambridge, Massachusetts.

YIU: Okay, so this is in Massachusetts. Where did you live at the time and what did you do?

MAY: We were living in Cambridge.

YIU: Right. In a suburban neighborhood?

MAY: I'm trying to—yes, after I—let's see, I left teaching and I was going to go to medical school. When I applied and—let's see, I got into Case (Case Western Reserve University), on the waiting list. Connie wanted to go to law school. She got into Northeastern law school.

YIU: Wow.

MAY: She started law school, and then, we decided to get married and it just didn't make sense for me to be in Cleveland and her to be in Boston.

YIU: So, you moved to—

MAY: We wanted to have a family and so we just got married. She left law school. She was at Northeastern, so, she quit law school and we had kids.

[00:15:50]

YIU: Oh, wonderful. How many kids do you have?

MAY: Two.

YIU: Oh, amazing. How old are they, now?

MAY: Well, let's see. Jessie was born in '80, so, she's close to forty. Ben is forty-two. They both have allergies and I think—

YIU: Oh, they both do?

MAY: Yes, they both have allergies. (This section has been redacted from the transcript.)

YIU: Oh, wow. Interesting. How do you make sense of that? Do you think it's related to you?

MAY: It could be. I mean, I guess, allergies can be inherited, right?

YIU: Yes. Going back to the Ford truck—so, in about 1985, you have purchased this truck for \$600 dollars. Can you tell me a little bit more about what happened afterwards?

MAY: Well, I drove it—I was in in a lot. I think I even might have used it for work, for a while. I can't remember now, but, I did spend a lot of time in that truck. I had a carbon monoxide sensor, I think I mentioned that.

YIU: Yes.

MAY: It was sitting on the front seat and it changed color indicating carbon monoxide presence. That's when I realized that the muffler was leaking, and I'd been exposed to that. I also found that the gas line was leaking. I'd been exposed to gasoline fumes and carbon monoxide for quite some time—whenever I was in that truck.

YIU: Wow.

MAY: That's how I explain the chemical sensitivity. After that, I mean, for a while, I couldn't go into hardware stores at all. I couldn't put gas into the vehicle. I got a new truck. I obviously got rid of that thing.

[00:18:13]

YIU: Yes. How long would you say it took you to—because, you said that you can, now—

MAY: Yes (unclear) years—it probably took a couple of years, anyway.

YIU: More than five, you would say?

MAY: I could—I'm not sure. No, I didn't have the truck that long. Let me think. It would have been—I had that truck when we were living on Antrim Street and Jessie was born, so, that would have been about '80. I must have had that for two or three years, anyway.

YIU: Two or three years. So, Jeff, what was your first sign of sensitivity? Did you just remember getting dizzy, or—what did it feel like?

MAY: Yes, I don't—it's funny, I think my biggest symptom was just the, sort of, brain fog, really.

YIU: Could you describe—?

MAY: I didn't get headaches, just, sort of, confusion.

YIU: You said brain fog. Could you describe a little bit about what brain fog feels like? How long does it last?

MAY: Just, it's hard to think. With me, it didn't last that long. It would, sort of, come on pretty fast and go pretty fast. Sometimes, it would last longer. I think, with pesticide, that would be more persistent.

[00:19:51]

YIU: Right, and, that was your first time of feeling these brain fogs, is that right?

MAY: Oh, yes. For sure.

YIU: How did you deal with it at the time?

MAY: No, when I realized what was happening, I would just really avoid exposures. I was pretty careful. I would carry—if I had to go into a hardware store or Staples or something like that, I kept the charcoal respirator with me.

YIU: I see.

MAY: I would just breathe through that. It was embarrassing. I never really put it on, I would just hold it and then put it up to my face.

YIU: You used the word embarrassing. Did you feel like people were treating you differently simply because you had a mask?

MAY: Well, they would have, but, I mean, I just didn't—it was never that obvious. So, I never noticed people treating me any differently.

YIU: I see. But, it felt like it was something that didn't match the social norm, is that right?

MAY: Yes. Today it would have been very different.

YIU: Of course, now that we're in COVID, right.

MAY: Everybody uses masks.

[00:21:17]

YIU: Yes. What was your initial impression of your brain fog? What did you think was happening, other than the fact that you needed to get rid of this truck, now?

MAY: Well, I had to be much more careful with exposures to things. We stopped using any kind of products with fragrances. The funny thing is, one of the things with clients, for a while, I'd always ask them—one of the first things was, can you walk down the detergent aisle? The detergent aisle was the

killer, usually. It was much worse, back then, when they had powder detergents, I think. With all the liquids, now, it's not quite as bad, but, the fragrance is still an issue.

YIU: I see. You perceived this exposure as something that you can kind of control by getting rid of the truck?

MAY: Right, yes, because, I was, basically—I worked for myself, so, I could always avoid any kinds of situations where I would be exposed to things. So, it wasn't that frightening for me, but, I can imagine that other people who have to go to workplaces and they're sensitized, it's a nightmare, because they have no control over their environment.

YIU: Did Connie ever drive the truck at all?

MAY: No.

YIU: Okay, so—wow. You're the only person that drove the truck and now you're the person that's experiencing these symptoms.

MAY: Right.

YIU: How did she first perceive your illness, or, your children?

[00:23:12]

MAY: Well, Connie has been very understanding about it all. I mean, she has asthma, so, she's been very, very sympathetic. She doesn't use any kind of fragranced products, at all. The kids are, well, pretty much the same, but, I guess, they're—my son uses a deodorant that's a little bit overwhelming.

YIU: Oh, I see. Well, your kids are kind of grown up, now. What is it like raising your young daughter with scent?

MAY: Well, she, actually, I don't think she had—neither of them—well, Ben had asthma as a kid. But, neither of them really had, as kids, any kind of health symptoms from fragrances.

YIU: Right. Did you have to have any, sort of, conversation with your children about scent use in your home while they were growing up?

MAY: Well, that's interesting—I don't recall, really, but I wasn't—we probably did. I just don't remember.

YIU: I see. They're pretty conscious, as you say, like, Connie doesn't really wear a lot of scent. So, it hasn't been—

MAY: Yes.

YIU: Right. Would you say that the conversation with asking for Connie to accommodate what your lifestyle needs to be changed was an easy conversation, or—how did it look like?

[00:25:03]

MAY: Well, she's just always been very understanding. In fact, we would always check out hotel rooms first if we have to stay anywhere—

YIU: Oh, interesting.

MAY: —just to see if I can breathe. Mostly, the fragrances can be a problem, but also, the allergens. The hotels are bad news.

YIU: Right.

MAY: We walked into one hotel room where they were installing new carpets. They were using some kind of adhesive. She came out and she lost her voice. She just couldn't make a sound. It was a laryngospasm. Her larynx swelled up.

YIU: Wow. You two still do regular travels, before this? I mean, before the pandemic?

MAY: Oh, yes, right. Not a lot, but, some.

YIU: Do you do any air travels? Like, international travel?

MAY: Occasionally, yes.

YIU: Does the airplane gasoline ever bother you?

MAY: Yes. Well, back then, I couldn't stay in hotels that were near airports because of all the jet fuel.

YIU: I see. Can you walk me through—you said that Connie would go in and, kind of, scent test these places, is that right?

MAY: Yes, well, we would go in together.

YIU: Oh, I see.

MAY: But, that one instance, she walked in there. I didn't want to walk in there.

YIU: Do you find it difficult to find housing while you're traveling, that are accommodating?

MAY: Well, yes, I would say so. We just, sometimes, we have to move. Like, one hotel was doing a lot of renovation work. We had to leave there. Interesting—the woman at the counter said we were the second couple to leave.

YIU: Oh, so you were—

MAY: Another time, there was one hotel—I was taking a class. I had to stay there for a week. I had to wear a mask, so, I was walking into the lobby with a mask on. There was an older couple checking in and when they saw me, they ran away.

[00:27:41]

YIU: Oh, why do you think they ran away?

MAY: Oh, because they were afraid. They thought—I'm sorry, I was inside. I was standing at the check-in counter with a mask on (unclear)—

YIU: Oh.

MAY: —was approaching the door to the hotel. They saw me with the mask, they turned around and ran away. They didn't want to check in.

YIU: For the fear, I see. Going back to earlier, you talked about getting rid of the truck and you went through a process of, I'm sure, eliminating certain products in your home. What did that process look like? Was it difficult to eliminate sources of exposure?

MAY: No, I think it—before we buy cleaning products, we would often sniff them, to see what the—we used to use all free, we always use free—supposedly—fragrance free dye or whatever, but, we used all free for a long time and that was great. (unclear) that started to bother me. They started using enzymes.

YIU: Then, that started to bother you?

MAY: Yes. I don't know if you are familiar with that enzyme situation in detergents. Procter & Gamble first started putting protein enzyme to help digest blood in laundry.

YIU: Oh.

MAY: They had up to, like, fifty percent, occupational sensitization and asthma. It was just unheard of. They traced it back to exposure to the protease enzyme they were using.

YIU: Oh, wow. I actually have not heard about this.

[00:29:32]

MAY: Well, it was a big—it was back in, like, the late sixties, seventies. It was in the papers a lot. Everybody said, Well, people are getting sick in factories. Then, people were getting sick at home. They get all kinds of studies and they never found any big connection, as far as consumers go, with allergy and asthma. They figured, less than a percentage of people are affected by it, or maybe it's even a tenth of a percent, but, I happen to be one of those people who are very sensitive to enzymes. And a lot of our clients are. We've had, actually, many clients who just switched detergents and all of their allergies went away.

YIU: Oh, wow. So, you—sorry, go ahead.

MAY: Yes, the irony—Seventh Generation has four different enzymes.

YIU: Oh, and they are the one that's really marketed as the—

MAY: Yes, right—big natural, organic—enzymes are free, organic and natural. So is viper poison—it's rattlesnake venom. I don't know. I think, it's a big issue for a very limited number of people.

YIU: Wow. So, you—

MAY: We always advise clients to avoid any kind of any detergent with enzymes.

YIU: You mentioned this enzyme sensitivity. What are some of the symptoms that happen when—?

MAY: For me, I just—I cough.

YIU: Oh, you cough.

MAY: Yes, that's the main thing for me. Some people get irritation from residue on the clothing—skin irritation.

[00:31:25]

YIU: Yes. Jeff, what would you describe as a serious episode or chemical exposure has been, since your interaction with that truck?

MAY: Well, the other—it's not so terribly serious, but, we were we were on an airplane to Italy at about thirty-some-odd-thousand feet or whatever. I went to the bathroom and there was a very strong fragrance emitter in the bathroom. They all do that.

YIU: Right.

MAY: So, I use a paper towel—I always keep a paper towel in my pocket, so that, if you breathe through the towel, the fibers will absorb the odor for a couple of minutes, at most. So, I was holding my breath and breathing through the towel, but, at 30,000 feet, you don't want to hold your breath. I dropped something and I leaned over very quickly and then I suddenly felt really faint. Actually, the steward caught me and I just keeled over. I was wearing a baseball cap. They went up, forward, to find Connie, because of the empty seat on the plane. They said, Are you with the guy with the baseball cap? She thought I had dropped dead.

YIU: Oh, no.

MAY: They gave me another seat on the plane with oxygen to breathe. I didn't get hurt, I was lucky. It was just—I guess it was the fragrance, was the cause of it.

YIU: Yes. Wow. It must have been such a small space, the lavatory?

MAY: Oh, yes.

YIU: Yes. I see. Did you ever bring up these episodes of sensitivity to doctors?

MAY: That's interesting, I don't think so. I didn't, because, I thought, I kind of understood it, and so, I just—

[00:33:46]

YIU: Right, and, how did you come to learn about chemical sensitivity as a term to describe your condition?

MAY: Interesting. I don't recall. I'm trying to think. I took a class at Harvard Extension on air quality. Jack Spangler taught that. He is a pretty well-known researcher. Maybe it was then. That's interesting, I don't recall. I've been on that MACI board, probably since then. It's been quite a while.

YIU: Yes. I definitely would love to turn to your activism soon, as well. You mentioned that you haven't sought help from doctors regarding chemical sensitivity. Did you ever talk to any alternative health practitioners to alleviate your symptoms, like, Chinese medicine?

MAY: No, nothing.

YIU: I see.

MAY: Because, I think, for chemical sensitivity, the most important so-called treatment is just avoidance. I don't know that there actually are any medical treatments for that. I just don't know.

[00:35:17]

YIU: Right. Would you describe chemical sensitivity as something that would affect your daily life and social life?

MAY: For me, not so much, really. But, again, I can imagine, for others, it would be tremendous.

YIU: I see.

MAY: I got over the really extreme sensitivity. I avoid being near strong fragrances and that's enough.

YIU: Right. So, in places like cinemas or concerts, you don't feel like—

MAY: No, I just get up and move. Again, I'm not nearly as sensitive, now, as a lot of clients I've had.

YIU: Yes. Do you have any relationships, other than in your consulting work, with folks who are chemically sensitive?

MAY: I didn't hear, you mean, other than the consulting? No.

YIU: Okay, so, you're not in any online forum with—

MAY: No, nothing like that. No.

YIU: I see. So, moving to talking about your consulting work, Jeff—you have a company, can you tell us a little bit about your company and your work?

[00:36:42]

MAY: Yes. We do a lot of investigations of odd problems that people have, and then, odor problems and allergy problems. We get quite a few referrals from pulmonologists, because they have patients who have symptoms that they can't really account for. They assume that maybe the environment is a problem. They want to have somebody look at the environment. So, I take—most of my work is with, I would say, in terms of health, would be related more to allergy and asthma than chemical sensitivity. Although, we do get calls. I'd say, the most dramatic one, I guess, was many years ago, actually. This woman was very sick—debilitated—with all kinds of neurological problems. I went to the house and just, I opened the door and the pesticide odor in the house was so strong, I had to get a respirator. I couldn't even walk in the door. There was this woman with a walker, breathing the air for twenty years in this house. She has all kinds of problems with it. The house had been treated with chlordane, which is a termiticide. They injected it into the concrete garage floor. They drill holes every two feet or so, and then they inject the chemical. By some horrible quirk of fate, her garage floor was somewhat above the level of the basement and her return air for her heating system had a big hole at the top of the duct. I looked through the mirror at the duct on top. So, the mechanical room was being depressurized by the air being sucked in and all the chlordane fumes were coming from the garage floor into the basement and being circulated by the heating system.

YIU: Wow, and, so—

MAY: They put in a radon system and that mitigated the problem.

[00:39:31]

YIU: Wow. What were some of the symptoms that this older woman was experiencing, living in a house full of pesticides?

MAY: She was really debilitated. She had all these neurological problems. She could barely walk. I mean, it was just unbelievable.

YIU: How did she find you?

MAY: That, I do not recall. I have to go back. Let me think for a second. Let me see. I don't even know if I can—

YIU: That's okay. Earlier you mentioned that you would ask your clients—one of the first question you would ask is, whether or not they can walk down the detergent aisle. Can you tell me a little bit more about why you asked that question and how common the answer—

MAY: Well, because the—I would say that most people with chemical sensitivity have a problem—one is because there's a lot of fragrance odor and the other one was because the detergent boxes would leak. There would be, like, powder on the floor. It could be enzyme residues. It could be just regular, irritating detergents, I'm not sure. But, a lot of it was just the fragrance.

YIU: Is it common, in your experience working with folks, that they would say it's difficult for them to walk down the detergent aisle?

MAY: Yes. Right. I think—I would say that there are a lot of people who are sensitive to fragrances that—but, they don't know that-- they've never heard the term chemical sensitivity. I've had a lot of clients who obviously have chemical sensitivity, but, they never heard the term. They never recognize that, really, as an illness.

YIU: Right. Is there any experience you can share with me about you telling your client or you sharing with your client about multiple chemical sensitivity (MCS) and how they perceive it? It's sounds like not a lot of people are readily accepting—

MAY: Readily what?

YIU: Readily accepting MCS as a real symptom and condition?

[00:42:11]

MAY: Right, yes, that's true. I think doctors are very, very resistant to applying that term to anybody, because they—classical toxicology. They have all the numbers for exposures to chemicals that cause health effects and, less than that is considered harmless. I don't think many physicians recognize it, so, they're really considered, like, wackos, kooks. That guy—they took his license away from that fellow in Texas, before he died. What was his name, in Dallas? I can't think of his name.

YIU: Does he run a toxin rehabilitation center?

MAY: Yes, right, in Dallas.

YIU: Yes, his name is escaping me, too.

MAY: Oh, yes. He did that for years, but he was considered a wacko. There aren't a lot of physicians that will recognize it. I think, finally, there is some European organization that classifies chemical sensitivity. I think they actually have a code for chemical sensitivity, but, in this country, I don't think we do, at all. Although, the CDC has a fragrance-free policy, supposedly.

[00:43:58]

YIU: Why do you think that is, that the U.S. has such a hesitancy in characterizing MCS as a medical condition?

MAY: Well, I think one reason is that a lot of people have very different symptoms. I think, for a medical diagnosis, if you itch or you sneeze, you can tell that's allergy. But, if you have a headache or whatever, it's not—anything can cause a headache. A lot of the symptoms that people experience for MCS, they vary a lot. Often, there's not one single source that you can point to. I mean, if you're exposed to some particular allergen, and you have allergies and you react, it's pretty clear that there's a treatment for that. But, it's not really, for chemicals—they can't do that.

YIU: I see. Going back to your interactions with your clients, when you do share with them about this thing called MCS, how do they usually react?

MAY: Fine. I mean, I think it's very—I can't think of a specific instance, but, I think they certainly feel better knowing that what they're experiencing is real and it's something that other people are experiencing.

YIU: I see. It sounds like there are a lot of experiences in your life, whether as a consultant or personally, that you have seen folks with MCS experience are invalidated by medical professionals. What do you think needs to be changed in those interactions?

[00:46:04]

MAY: Well, I think that it's something that the medical profession should recognize. Even though they don't understand the, sort of, etiology of the whole thing, it's just so common that, you have to begin to say, Well, there must be something real going on. There's a few theories out there on how this is happening, but, I'm not that familiar with them. I think, some trigeminal nerve activation explanation. I don't know. I haven't really kept up with that.

YIU: Right. You said that, mainly, you do indoor air quality and thinking about allergens and things like that. Have you done any work specifically related to chemical sensitivity or environment exposure?

MAY: Yes, some. Actually, one of the big problems, now, we're facing, is exposure to chemicals from spray foam. Are you familiar with that? The spray polyurethane foam?

YIU: Yes, for insulation?

MAY: Yes. Well, I've had a lot of law cases like that. I must have had over twenty now.

YIU: Wow.

MAY: In some of these situations, people moved out of their house. They couldn't live in the house. They got so sensitized to it. It's pretty—

YIU: Did you say law cases?

MAY: Yes. There have been a lot of lawsuits.

YIU: Oh, I see.

[00:47:43]

MAY: People who couldn't live in their house. In fact, I was supposed to testify—in a couple of weeks, I think. I haven't heard back from the attorney. This couple put spray foam in this really beautiful, big house in a very expensive part of town. They couldn't go into the house after that because they were so sensitized. They were in the house for a while, but then, eventually, they couldn't go back in. I actually tested it. There were clearly chemicals. I took air samples of volatile organic compounds in the attic, where it was applied, and the second floor and the basement. Clearly, the concentrations were highest in the attic and there were some characteristic compounds that were present in the foam that were in the air. So, it was obvious. That lawsuit is ongoing. The people sold the house to a contractor and, as luck would have it, I got called by a builder and he wanted to know if I would look at a house for that spray foam and if there was a problem. When I got to the house, it was the same one as the lawsuit.

YIU: Oh, wow.

MAY: So, I called the client up and he said he didn't want me to have anything to do with it, so, I told the builder I couldn't work with him. I found out, later, that he took the entire roof of the house off because he couldn't—

YIU: He couldn't fix it.

MAY: He couldn't really fix it. They just took the roof off. Then, they added some extra rooms. They increased the value of the house by making this plush third floor. That was an interesting place. Quite a few people who are sensitized to that stuff and it's awful.

YIU: Yes. Would you say, in your experience, that folks—like how long do these legal cases go on for? Do you know of anyone—

MAY: Oh, years.

YIU: —that has gotten what they wanted?

[00:50:06]

MAY: No. Well, I can't think of any. It's sad. They go on for years. The thing is, these things are very hard to prove. Like, in this particular case, the wife used to have a lot of mothballs in the house. So, the defense is claiming that the mothballs made her sick.

YIU: Interesting. So, in your experience, it's just a very strenuous and long process.

MAY: Yes. It's very, very difficult. The manufacturers deny any responsibility. The levels of the chemicals are—they're not that high, and there's no—people ask me all the time, Is it toxic or dangerous? I'm saying, Well, dioxane is one of the chemicals, actually, and that's considered a carcinogen. But, there's not a high concentration of it. It's very low.

YIU: It sounds like, Jeff, you're really involved in advocating for folks rights, whether it's in your personal work, or—do you do any activism outside of your consultancy work?

MAY: No, not really. I mean, I participate on the boards, and I give a lot of presentations. Now, I'm sort of a teacher, so that's what I—every year, I do a bunch of presentations at different conferences.

YIU: Yes. Can you tell us a little bit more about where you give these presentations and what they are about in relation to chemical sensitivity?

[00:51:55]

MAY: Yes. It's mostly about allergens in general, but sometimes—I mean, I, generally, will mention, like, a case history, a situation where people were sickened by something. I got an interesting case. This woman was chemically sensitive. They had no fragrances of any kind in the house and she was having problems and her kid actually was having some problems in the house. We took a volatile organic—VOC—test, in the house. There was a surprising level of a whole bunch of different fragrances in the

air. She couldn't believe it, because they didn't use any fragrances. It turned out that they had recently remediated their crawlspace and they put this really heavy plastic vapor barrier down. The plastic vapor barrier was made from recycled shampoo bottles.

YIU: Oh, wow!

MAY: The plastic was off gassing. Talk about recycling.

YIU: That is fascinating. Do you—

MAY: Yes.

YIU: Do you have thoughts about that? I've really never heard of that, and—this very interesting intersection between the good side of recycling and the lack of consideration of scent exposure.

[00:53:30]

MAY: Right, yes. It's a strange one. I mean, I get it—actually, another product that still really bothers me a lot is anything rubber made in China, you know, rubber wheels. I had to cover my spare tire in aluminum foil. There's a finish that's called CAB, cellulose acetate butyrate.

YIU: Okay.

MAY: That's a clear finish they use on furniture. Anything that has that word, butyrate, in it, means it's part of butyric acid. Butyric acid is what gives the odor to vomit. If you don't manufacture the finish properly, there's going to be left over butyric acid. This poor fellow was having a horrible problem with this odor in this house that he had economy purchased. He had bought all the same furniture from one of the big furniture houses there. It was all brown, stained furniture with finish on it. Every piece in the house smelled like puke. You would smell it, you could get this low-level smell in the house, but, unless you stuck your nose to the piece of furniture, you wouldn't know.

[00:55:17]

YIU: Right. Wow. So, Jeff, what do you think is the current state of regulation in terms of the recycling industry, of being able to manufacture products that are like this?

MAY: I have no idea. I know some, like, one of the biggest products that's being recycled is called polyethylene terephthalate, I think. It's the clear plastic from soda bottles. They break that back down to the original components so it doesn't have any kind—it's not the way, if you took plastic from shampoo bottles and kind of melted them, they would still have the fragrance in the plastic. So, the beverage

bottles, they actually break down into the components and then they remake them, starting over again. I don't know what kind of requirements, if any, exist, and what can be in those materials that they recycle.

YIU: It sounds like there have been several cases in your work that folks react to building materials that are recycled, is that right?

MAY: I wouldn't doubt it. Well, one of the things, I know, that really bothers me a lot are these—they use recycled tires for some things. They put them on playgrounds and they make some mats out of them. Those things, they off-gas sulfur compounds, which are kind of annoying. That's a big material that they recycle.

[00:57:23]

YIU: Wow, this is so illuminating. Thank you, Jeff. In thinking about, for folks that don't know who you are, you are on the board of the Chemical Sensitivity Foundation. How did you find your way to the Chemical Sensitivity Foundation?

MAY: I think that was Alison Johnson. I think she found me, I guess, because of the talks that I give, that sort of thing, and the books that I've written.

YIU: Yes. Can you tell us a little bit about your publications and your textbooks, as well as your work on the board?

MAY: Well, I guess, I'm deep down, really, a teacher and I want to help people. I think that's, basically, what all the talks are about and what the books are about is to really just spread the word about the kinds of health problems that you can have from their homes and places of work and schools. That's most of what I'm trying to do.

YIU: Yes. Do you consider your work in outreach and educating, as well as, even, testifying for your clients as activism or community organizing?

[00:59:00]

MAY: Oh, I don't think of it as activism. I suppose you could call it that.

YIU: Well, then—

MAY: Actually, I got put on—I belong to an organization called IAQA—Indoor Air Quality Association of America. They, kind of, joined up with ASHRAE, for a while—American Society of Heating, Refrigerating and Air-Conditioning Engineers. I was put on a committee to create a position

document on air quality for ASHRAE. ASHRAE is run by most of the mechanical industry, so, they do a lot of amazing things, but, at the same time, they're very protective of their industry interests. It's an industry organization, although, on the surface, it's a public organization. My job for this position document was to write something about air conditioning and mold—at least, I thought that was my job. I wrote this thing up and, so, they added it to the position document. Then, a couple of weeks later, I got another draft of the document and that paragraph was missing. I happened to—I had a friend who was a very well-respected, renowned architect and I mentioned to his wife that my paragraph had been omitted. I think she must have told her husband and he must have relayed that to ASHRAE, because he's an indoor air quality professional, as well, and an architect. So, he said, You should really put the paragraph back—I'm assuming. I don't know that this is what happened. The next round of documents we got back and there was—my paragraph had come back and it said, mold is in every air conditioning unit. Then, a couple of weeks after that, I get this notification that the whole committee has been disbanded.

YIU: Oh, wow.

MAY: They gave up on the position document because—well, my feeling is that, it's just too sensitive. The air conditioning industry denies that there's any health issues associated with air conditioning, and they don't want that out there so they just took the whole project off the shelf.

[01:02:00]

YIU: Oh, wow. That's so interesting to think about how capitalism and the air conditioner industry tries to contain information.

MAY: Yes, absolutely. I mean, the fiberglass industry people say that mold can't grow on fiberglass. Well, it's true—it's glass, it's a mineral. But, the fiberglass is dirty and that's what the mold is growing on. They maintain that the fiberglass—there have been so many studies on air conditioning units where there's mold on the insulation, but, they continue to put fiberglass insulation in the air conditioning equipment so—pathetic.

YIU: You are so knowledgeable, Jeff. These are some of the materials that I've, actually, never come across in thinking about exposure. So, thank you so much for that.

MAY: Yes, well, good.

YIU: Yes, you just offer such a different set of questions for me, now.

MAY: Yes, well, I'll tell you another crazy thing that I've seen into some of these bizarre—these are mostly odor problems, but there was, for a while, I was getting a lot of calls about odors. The odors were

coming from the insect screens on windows. There was only one manufacturer in the country, of all the screening. It's a fiberglass plastic resin composite. When the sun hit it, it would decompose and produce this very peculiar odor. For a while, I was getting a lot of calls. I, actually, talked to the VIP at that company and they recognized that it was a problem. They paid—one woman got about \$5,000 just for testing because she had gotten multiple tests in her house. She couldn't determine the odor. Then, they would always replace the screens. They did that for about three or four years. Then, one year I sent the client down there and they said they had never heard of the problem.

YIU: Wow.

MAY: Unbelievable. So, they stopped paying out. Somebody else came on board and they said, We're not going to deal with this anymore.

YIU: I see.

MAY: Then, another very strange one: I had these people—the funniest one was, this woman said whenever her relatives came to visit her house during Thanksgiving and Christmas, the house would smell like dead fish.

YIU: Dead fish?

MAY: I went around the house and, what happened was, the difference—when people were visiting, a lot of lights would be on in the house. I got up on the ladder and she turned the light on in one of the rooms and I actually gagged from the smell. There is an insulating material around every light bulb base. The base is called an Edison base; it's the metal threads. The metal threads have porcelain nylon insulator around it, and the nylon was decomposing.

YIU: I see.

MAY: Nylon is made from hexamethylene diamine and sebacic acid. Diamine smells like dead fish. So, when that plastic was heated by the light bulb, it would produce this dead fish odor. I've had a bunch of houses where that was a problem. I had another one where these people had never had a smell in their house until they had a contractor come, and they started doing some renovation work. It turned out that the contractor wasn't really the problem—it was the light fixtures in the basement. No one was ever in the basement, but, when the workers were in the basement the lights were on all the time. So, the Edison base insulator started to decompose and that produced that dead fish smell.

[01:06:23]

YIU: Wow. That's—

MAY: There are probably many, many things like that, that I'm not aware of, that anybody's aware of, and they just happen.

YIU: Wow. That's so interesting to think about how recycled material has really become sources of exposure afterwards—

MAY: Yes.

YIU: —and how you're, kind of, this Sherlock Holmes of detecting where it comes from.

MAY: Well, I forget, there was something else—there was, actually, some serious exposure from some other recycled material they were using on—I don't remember, now, I think it was on football fields. There was a whole, big—I can't remember what it was. Yes, it's very interesting, getting to the bottom of all these.

YIU: Yes. I realized that we're up an hour now. Are you doing okay? Can we wrap up within the next twenty minutes? Or, do you think—?

MAY: I think it's better, yes. I don't know if you got all you want, but, yes, I think I have to get going.

YIU: Okay. That sounds great. I haven't gone through all of my questions, and I think that I, actually, might need another interview opportunity with you, if that's possible.

MAY: Yes, that's good. Why don't you email Connie, because she does all the scheduling.

YIU: Okay, that sounds great. Thank you, Jeff, for such great information. I'll be in contact with Connie very soon.

[01:08:08]

MAY: Okay, take care.

YIU: You, too. Bye bye.

(End of May 12, 2020 interview)

Interview of Jeffrey May
SESSION 2 (5/15/2020)

[00:00:00]

YIU and MAY: (conversation on other topic)

YIU: I'm glad you got it all done, and, I'm thankful that you made the time to speak with me.

MAY: Sure.

YIU: Do you have any questions before we get restarted, again, or shall I jump right in?

MAY: No, just get started. Go ahead.

YIU: Perfect. Last time, I know that, when we spoke, you mentioned that you haven't talked to doctors about your condition, but, I forgot to ask you, have you ever received any mental health support?

MAY: No.

YIU: Okay, so, how are you navigating this shift in your health?

MAY: I just was careful, that's all.

YIU: Yes.

MAY: As I said, I wasn't in a position where I had to be in the workplace and be exposed to things that I didn't need to be, so, it was a lot less of a burden for me than for most people.

YIU: Right. How—because, it's interesting you mention that, because of work and workplace environments, since you own your own business. Do you think that class affects people's experience of chemical sensitivity?

MAY: Class?

YIU: Yes.

MAY: You mean, as in—?

YIU: As in, socioeconomic status.

MAY: Oh, what do I think? Well, I mean, I suppose, people who aren't well off, it's going to be a lot more difficult. I think, when dealing with people who have MCS, that they—people who can afford it, get a lot of help, and people who can't, probably don't. They may not even know that they're sick.

YIU: Right. Since you do work with people who have chemical sensitivity or react to certain exposures in the environment, have you noticed any patterns in gender, race or class in affecting people's experience?

MAY: Well, I do think—I mean, I don't know about class, so much. It's, just—really, women seem to be affected a lot more than men, maybe two to one.

YIU: Oh, interesting. So, you've worked with more women in your work than men?

MAY: Yes. I think people who belong to the organization where I'm on the board, it's mostly women. There are a few men, but, generally, at least two to one, maybe more.

YIU: Yes. That's an interesting observation. What do you make of that?

MAY: Well, I think it may be, actually, something just, kind of, genetic, wired in. I know there's an outfit in Pennsylvania, in Philadelphia—Monell Institute for Chemical Sensors or something like that. I forget. They've, actually, looked at people's sensitivity to fragrances, and, women of childbearing age are more sensitive to odors than men. Are you familiar with this Monell Institute?

YIU: No, I actually have not heard of them.

MAY: Well, I guess—let me think of that woman's name now. Well, they looked at groups of men and women of different ages. They exposed them to benzaldehyde, which is almond oil, basically, just nice smelling fragrance. They looked at their odor threshold. What they found was that—they did, maybe, twenty sessions or something, I don't know how often, maybe once a week or, whatever it was, once a month. Over time, the men's odor threshold didn't really change at all and women decreased by three orders of magnitude. So, women of childbearing age could detect the odor of the benzaldehyde at 1000 times lower concentration than the first session.

YIU: Wow. So, there's a buildup, it seems.

MAY: Well, no, I think it's in the gene, so to speak, that women will be more sensitive to odor. I think it's just protective of infants that—women are more responsible of taking care of kids than men. They have to be aware of the smell of things.

YIU: Right. Since I haven't heard of this study, did they think about race, at all, in this study?

MAY: Race?

YIU: Yes, was it just a collection of age?

MAY: I don't think so. Let me see if I can—I can't find it. Monell Chemical—let me see if I can find that article.

YIU: Right.

MAY: I'm not spelling that right.

YIU: Maybe I can find out, on my own.

MAY: No, I'll just take a second. Bear with me.

YIU: Okay, thank you.

MAY: Institute for Chemical Senses. Okay, let me see. I'm pretty sure it's M-O-N-E-L. This one is—no, it isn't Karen (unclear), that's not the author. Here it is, it's Monell. Okay, it's M-O-N-E-L-L.

YIU: Oh, I see, Monell. Okay.

MAY: Yes, and—let's see. Do I have that paper? I must have that paper. Let me see something here.

YIU: Yes, I just find it intriguing, because, we've spoken with a lot of folks, and they're often folks of a particular race. I've just wondered if, in your experience, as well, there's consistency in who comes to seek for your help for MCS, as well?

MAY: Oh, well, I mean, mostly, it's white people.

YIU: Yes.

MAY: I don't know if I've ever had a client that was—

YIU: A person of color?

MAY: —a person of color. I don't think so.

YIU: Wow. So, it's—sorry, go ahead.

MAY: Go ahead. I'm just trying to find the paper. I wish I could remember her—they list a million papers here so I'm just going through by the year. Oh, I can't remember her name. I think it would be interesting for you to look at something like that. Let me—

YIU: Most definitely. I can also do further research when we're done on the phone. I don't want to—

MAY: Yes, but, I know I have the paper, so, I just have to find it, that's all.

YIU: Oh.

MAY: I probably have it in the odor threshold or something like that. Let me look. That would certainly be something to look at. Some people feel that the organization sort of, politically, is to the right. It's all run by chemical industry, I think. Let's see.

YIU: You were saying, some people think that the Monell Institute was run by the chemical industry?

MAY: Well, yes, I don't know. I read that someplace. Okay. The name of this paper is called “Gender-specific Olfactory Sensitization: Hormonal and Cognitive Influences.” Now, that MAY: be even a different one, but that's by Pam Dalton. Pamela Dalton—D-A-L-T-O-N. It's the Monell Institute. I think that was the paper. Okay.

YIU: Thank you for getting that to me.

MAY: Sure.

YIU: Yes, I think I've also had an experience of, mostly, talking to white folks about their experience of chemical sensitivity. I can't quite figure out why, either, so I was interested in your personal experience.

MAY: Yes, no, I think that that's definitely been my take. I don't know why. That's an interesting—I'd never thought about it.

YIU: Right. Yes. You said you haven't gone to any online support group, is that right?

MAY: I have not, no.

[00:12:31]

YIU: Right. Then, you wouldn't know what racial demographics would be, either.

MAY: No.

YIU: Yes. But, on your board, what is it like?

MAY: Well, there's always, like, a couple of men and then five women, mostly.

YIU: I see. Do almost all folks identify as white?

MAY: Yes, definitely. On the board. Yes.

YIU: How did you get onto this board? Was Alison Johnson—

MAY: I don't know. Good question. I think, probably, because I've given—this is for the Chemical Sensitivity Foundation. It's probably because I had given a lot of talks and the woman who runs that has been to some of those conferences. I'm not sure about the other one.

YIU: Right. Your experience in sitting on these boards—what would you describe this work as? Would you describe it as activism? Would you describe it as community building?

MAY: I mean, as far as, my part in it, you mean?

[00:13:41]

YIU: Yes.

MAY: Yes, it's not so much activism as, I think, just—I suppose it's just helping, really, trying to help people. I don't think of myself as a, sort of, rah rah activist out there.

YIU: You mentioned earlier, you've always been keen in teaching and that a lot of your work is really about information sharing.

MAY: Correct.

YIU: (unclear) people and you've written books about, really, the impact of environment and chemical exposure and indoor air quality. In thinking about that, would you consider that as activism or would you describe these as just information sharing that you find to be necessary?

MAY: Yes. I don't think of it as activism, really.

YIU: So, sharing this information, do you find others that respond to you after reading your papers or books? Or, did anyone inspire you to do the work that you do now?

MAY: Not for the chemical sensitivity part, but, I guess, for indoor air quality in general, I guess, Jack Spangler—the guy that I mentioned that teaches at Harvard—and, also, Thad Godish, who had written one of the first books on indoor air quality. He was a teacher at, I think, Indiana State, or something like that.

YIU: Right. We've talked a lot about your work as someone who is, like, this chemical detective, but also, your work in sitting on these boards and doing work of information sharing. Have you found particular strategies to be useful?

MAY: No, not—I mean, I think that convincing people to believe that it's real—it's very difficult. It's hard enough, just to—we actually, this is, sort of, an interesting thing. Even with air quality, it's usually women who are home more, so, they have more exposures to problems in the home. Very often, the husbands are very—the non-believers—and very non-supporting. We've actually had two or three divorces where the women were very, very sick and the husbands didn't really believe them or even that there was any problem. Then, I would do the investigation and find out that there are a lot of problems and that their wives are not really crazy, but, they're very sick. It's really difficult in relationships, when—I would say, in more relationships, people are a little hostile, but, in many, the partner is very sympathetic.

YIU: Right.

MAY: We've also had women who didn't believe that their husbands were ill. So, it's both ways, but, I'd say, again, it's mostly husbands who don't believe their wives.

YIU: That's fascinating because I've interviewed some folks that have partners and some folks that do not, and, as you say, it's a variety of experiences that just really depends on how sympathetic someone is.

MAY: Right.

YIU: It's interesting that you highlighted how much time someone spends at home, relating it to their exposure, and noticing it. You describe that there are non-believers. Why do you think it's so difficult for people to believe?

MAY: Well, I think there's probably two aspects to that. One is that many people who are chemically sensitive, their reactions are so extreme. And, so, you have other people who either don't smell anything

or there's a little bit of an odor, but, it just doesn't bother them, at all. They just can't understand why somebody would be having that strong of a reaction to something.

YIU: Yes. You said that you have seen folks who have gotten divorced from this. I've asked about you and Connie's experience and it seems Connie is really accommodating. Do you think that it poses a specific strain within families and romantic relationships?

MAY: I would say so, yes. I think it's very, very difficult for people. If one person is sick with either extreme allergy or chemical sensitivity, it's very difficult. I think people tend to be more understanding if it's their children.

YIU: Interesting. Could you describe one instance of this difference of concern between, for their partners versus for their children?

MAY: Well, they worry. I think, if parents have kids like that—I mean, I actually have them, I just made an appointment yesterday for a situation like that. The daughter is—actually, it's sort of interesting. She has Lyme disease and mold sensitivity. I've never heard of this but she's, like, acting out. She is a ten-year-old girl and she's just getting very, very angry. Not so much any other symptoms, except, very angry. It seems to be—they think it's since they moved into this house. I think she's getting to be a teenager, but, we'll see.

YIU: Right.

MAY: That's one of the hard things about really diagnosing chemical sensitivity. I think you said that before, but, I mean, it's just that people have such different symptoms. So, if you come to a doctor and they see ten patients with chemical sensitivity but they all have different symptoms and, so, it's very hard to ascribe it to one illness.

YIU: Right. Yes, that's interesting that this young girl might be experiencing something that's related to environment exposure. Lyme seems like something that comes up a lot—

MAY: Oh, yes.

YIU: —along with chemical sensitivity. Have you found that, yourself?

MAY: Yes, I think a lot of our clients have chronic Lyme—a lot of them. That seems to have really wide-ranging effects on their health (unclear)—

[00:21:22]

YIU: Right. Sorry, you said, wide-ranging—?

MAY: Wide, just, effects—like, sensitivities to different things and all kinds—I couldn't even list them all, but, I mean, it's just a very strange, strange thing.

YIU: Right. Wow. This is interesting, because, I didn't ask you—do you, yourself, other than allergies, have any health conditions, in addition to your sensitivity?

MAY: Well, yes, I have asthma.

YIU: Okay. But, nothing else that really—?

MAY: Well, I have a whole raft of things that really affects the MCS. And, I—

YIU: Would you be comfortable sharing how it influences your body's reaction to chemicals?

MAY: Well, I don't understand the question. Sorry, how—?

[00:22:25]

YIU: Right. So, you said that there's a raft of other health conditions that affect your MCS.

MAY: No, no, I didn't mean that. No, I didn't say that. Oh, I see. No, no, I was just saying I have a lot of health conditions. I don't want to go into it. But, I mean, I'm seventy-six, so, they add up over time.

YIU: Oh, wow. You sound so young over the phone, too.

MAY: Good.

YIU: Yes. So, nothing in particular, you would think, that affects your body's reaction to chemicals?

MAY: No.

[00:23:10]

YIU: Okay. You've made so many observations of how sensitivity affects other people's lives. How do you think your chemical sensitivity affected your life the most?

MAY: It's hard to say. I guess, it's just, I have to avoid certain places, really. That's primarily—I mean, I've been lucky because I understood, kind of, what was happening from the beginning, and I didn't think I was crazy.

YIU: Right.

MAY: I think a lot of people just don't understand any of it, so, they have a lot of problems with it. I would have to say, one thing that people who have chemical sensitivity—they can be very hostile because the world doesn't understand them. They're often, sort of, initially, even hostile towards me, even though I'm understanding, because, it's just, they are sick and bothered by all of these things, and their life is really destroyed by it, and it's not affecting other people. It's interesting, the people who participate on the board seem to be a lot more understanding, and I don't see any of that hostility there. But, in a lot of the clients, they're just very—they don't trust people because, somebody will say, Oh, we don't use fragrance, and then, there will be some odor, some obscure deodorant, or something like that, whatever, and there is a big impact from that. It's funny, Connie and I can almost tell, when people just get on the phone, before they tell us what's wrong, whether they have chemical sensitivity. Some of them—

YIU: Wow, how can you tell?

MAY: There's a certain way they describe situations that they're in, and, the way they talk. It's not always true, but, in a lot of cases, it is. I mean, because, they're so used to being negated, really. You're not starting on an even plane, ever. It's always, they're suffering and nobody understands them and, who are you, you know?

YIU: Right. In your experience, you said, a lot of these clients start out to be hostile and defensive, at first—kind of as a protective mechanism, is what I'm hearing. How does that relationship change with you and your clients, over time?

MAY: Well, I think that people realize that I understand the situation and that I am a sufferer, myself. I think that really seems to help.

YIU: Right. Have you built any relationship with your clients or do you usually just help them and that's it?

MAY: Most of the time, if some people come back many times. Others, not.

YIU: I see. I remember, in the beginning, you said that a lot of people, when they have come to find you, they don't know that they have multiple chemical sensitivity.

MAY: That's true, too. They just didn't realize that there was a term for what they were suffering.

YIU: Right. How do people react to that recognition or new knowledge? Do they ask you more about it?

MAY: No, I refer them back to the organizations, if they've never really gotten help or even talked much with anybody about it.

YIU: Right. Now, wrapping up, I would really like to ask some of the questions about what we were talking about in the beginning, which is, how these recycled materials being produced that are not regulated by these government policies and things like that. Do you think that there are steps that could change our relationship to those materials?

MAY: No, I mean, I suppose they have to do some more testing, but, it's unfortunate that there's so much emphasis on recycling that people sometimes forget that there may be some toxic component to it. I just read another thing about that. I can't remember. No, I guess not. No. There was that—I think we had talked about that—there was something that was spreading out on football fields, or something, that was making people sick. It was probably the tires, but, I don't remember.

YIU: Yes, and the shampoo bottles, that become (unclear)—

MAY: And the shampoo, yes, that was bizarre. That was really bizarre.

YIU: Yes. Other than people not knowing the true operations beside recycling, what else is the cause of this very—it just seems like a terrible decision. Do you think it's the company that is using loopholes, or—?

MAY: No, I don't think so. I just think that—again, it's not something that most people think about. People think of fragrances as been a wonderful thing and so they spray them into lobbies and they spray them in bathrooms, anything. They put it on garbage bags.

YIU: It's interesting that you say, we think of fragrance as a good thing, right?

MAY: Yes, people love fragrance. I mean, I did. I grew up working in a drugstore. I loved perfume.

YIU: Why do you think that is—that we have this idea that perfume is a good thing?

MAY: Well, I guess, flowers have—sweet odors like that are nice.

YIU: Yes. Do you think that there are more ways that we can change people's understanding that, perhaps, not all good smells are good for all people?

MAY: Well, did you see that Steinemann paper, at all? She did one on fragrances. Have you seen that?

YIU: Yes.

MAY: You have?

YIU: Not in depth, but, yes.

MAY: Okay. Yes, because she has written a bunch of stuff on effects of fragrances. Let's see. Okay, I'll send you a few of these, too. (unclear) CDC (unclear)—(This section has been redacted from the transcript.)

[00:32:34]

YIU: Thank you very much.

MAY: What?

YIU: Thank you.

MAY: I sent you the Dalton paper.

YIU: Yes, I just checked my email and saw that. Thank you, Jeff. Do you, personally, think that—because, one of the examples you gave was, in hotel lobbies, they spray the scent. Do you think that scent is an accessibility issue?

MAY: Well, yes, I guess. But, again, it's just a very limited number of people.

YIU: Right.

MAY: I don't think it will reach that level, just because—I mean, I suppose, I would bet that there are more people who are sensitive to fragrances than there are people who need wheelchairs. But, it's just, you can see somebody with crutches or a wheelchair, but, if somebody, they're suffering from exposure to fragrance, how are you going to know?

YIU: That's true. It's a very invisible condition, for sure.

MAY: It is, definitely.

YIU: Do you think that that makes it more difficult?

MAY: Oh, yes. Again, they really can't diagnosis it. It's very, very difficult to diagnose. I think there is actually, as I said, I think, in Europe, they have some classification for MCS, but, I don't think they really do here.

YIU: Right. Well, it's interesting that Canada and Europe definitely have more recognition—

MAY: Yes, that's true.

YIU: —of the illness. Why do you think that is?

MAY: Well, maybe the chemical industry isn't as strong.

YIU: Yes. I see.

MAY: The chemical industry is really, really powerful.

YIU: Do you have some examples of how chemical industry in the US is powerful?

MAY: Well, they do—I mean, I guess, Congress really gets moved by lobbies and so the chemical industry lobby is pretty strong there. Look at what it's doing—they are gutting the EPA (Environmental Protection Agency) of all these regulations that—they just recently stepped away from one of the things in the Obama administration that they were supposed to do. I can't remember what chemical it was, but, they're out there.

YIU: Yes.

MAY: I mean, I'm a chemist and I love chemistry, but, I'm not so crazy about what the industry does. The pollution—it's unbelievable. They've been changing all the fluorocarbons, the freons, so, they come up with some—now, they call them green, the new ones. Now, they're finding these chemicals—the fluorinated chemicals—in the Arctic, in the ice cores. They're finding all these chemicals that they just started using a couple of years ago, already, that never break down, that are supposedly toxic, these fluorocarbons—PFA, perfluorohydrocarbons.

YIU: Yes, it's interesting that you bring up the chemical industry, because, the last question that I would ask is, what do you think some of the changes should be to change our relationship with chemical capitalism?

MAY: It's difficult, because, a lot of the products of the chemical industry are such a convenience to people. So, it's difficult. When you look at Teflon pans, I mean, cooking with Teflon—that was such a great thing, and now, they are finding people getting sick from—the manufacturer and even some people think you get sick from eating food that has been cooked on Teflon. I suppose there has to be more government oversight of—they're so backed up on studying any of these chemicals and health effects and things. They were supposed to study all these different chemicals and it's taking so many years. So, that would be certainly one way—just, to have more testing of products and chemicals before they get widespread use.

MAY: Yes, and, you were saying, it's really difficult because of the hold that these companies have in lobbying and things like that. If we were in a dream world, what do you think would happen?

MAY: Well, I guess they would look at the environmental impact of things that are out there. Then, limit the use if there is a problem. One interesting thing—they're using all these beads. Have you heard about these? There are these microscopic beads that they put in cosmetics and—

YIU: Yes, the exfoliation thing.

MAY: Yes, right. Now, they're finding them in fish and birds.

YIU: Right.

MAY: Somebody has to think about where all these things go.

[00:39:40]

YIU: Yes. Well, you're really pointing out this connection between chemicals in the environment and other species on Earth, as well.

MAY: Well, yes, for sure. Yes. The beginning of it all was—there is that woman who wrote *Silent Spring*. That was the beginning of the environmental movement, really—about the DDT and the bird eggs.

YIU: That's interesting that you pointed out that history.

MAY: Yes. She started the whole thing.

YIU: Yes. Are there any questions that I haven't asked you, Jeff, today, that you would like to add on the record?

[00:40:39]

MAY: No, I don't think so.

YIU: I'm really thankful for your time and your expertise and talking about these chemicals with me, today.

MAY: What actually happens with this? Is this something that is recorded or that it's going to be—?

YIU: Yes.

MAY: Does it get written? Or, what will ever happen? It will just go into some archive?

YIU: Yes. Our intention is to transcribe our interviews. We have a very small team of transcription, right now. Given that we can't hire new people, because our office is not currently open, we're a bit backed up in transcribing. In the end, your interview will be transcribed into text. It will be posted online, with your permission. I will send you a copy of the legal agreement in mail. I have asked Connie about your mailing address, already. You would sign that, which means you agree to us sharing your story via this recording, and the last one, and the transcripts, as well, so that folks can access these stories, if they would like. Then, in the end, these oral history interviews will also be used as a part of a research brief and policy brief in helping others really understand the impact of chemical illnesses and chemical exposure.

[00:42:12]

MAY: Okay. All right. Well, good luck with the project, Nic. Thank you.

YIU: Thank you so much, Jeff.

MAY: Look forward to getting that. I don't know if I'll be able to read it.

YIU: Yes. I mean, of course, you'll be able to read it if you want to.

MAY: No, I mean, it's just—it is long.

YIU: Yes, of course. That's why it's great that we record it so that people can just listen to it.

MAY: Oh, I see. Oh, okay.

YIU: Yes. I'm definitely going to send you that thing in the mail.

(The remaining section has been redacted from the transcript.)

(End of May 15, 2020 interview)