

Oral History with Jacqueline Rice

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Interview with Jacqueline Rice
Session 1 (5/16/2019)

STEVENSON: My name is Grace Stevenson, and today I am here with Jacqueline Rice on May 16, 9:30am, doing a phone interview. I'm at the Center for the Study of Women at UCLA. Jacqueline, would you mind stating when and where you were born?

[00:00:20]

RICE: I was born (at the Great Lakes Naval Hospital) in Shields Township, which is near Waukegan, Illinois. October 3, 1953.

STEVENSON: Perfect. Could you tell me a little bit about your parents?

RICE: My parents had me when they were really young, nineteen and twenty-one, and my mother was a stay-at-home mom for a while. Then she worked off and on as I was growing up, as an office manager and at radio stations and things like that. She was a go-getter: funny and assertive, and she likes to follow causes. I take after her in that way. My dad was a firefighter for his whole career. He was a decent guy, you know? That's about it.

STEVENSON: Did you live with anyone else growing up? Any siblings or relatives?

RICE: I had three younger siblings.

STEVENSON: Perfect. And were those sisters, brothers?

RICE: I have a brother who's two years younger, a brother who's eight years younger, and the sister's ten years younger.

STEVENSON: Were you close with your siblings growing up?

RICE: Pretty close, growing up. My sister and I got closer when we were older because of the age difference. I left home when she was not even ten, but we're closer now.

STEVENSON: What about your parents?

RICE: My dad was a little bit distant, but I was close to my mom.

STEVENSON: You said that your mom was big on following causes, if I got that correct. Were there any specifically that you can remember, growing up?

RICE: She was involved with the local group; it was Women Against Rape, back in the '70s here in Milwaukee. She was integral to that group. She was also interested in women's issues in general; she actually filed a job discrimination suit, so she was not one to sit in the weeds and just let things happen. She was also interested in children's causes. And politically, she was involved. She voted, and I think she worked the phones a few times.

[00:02:58]

STEVENSON: Was your dad involved in any of those causes as well?

RICE: Not really.

STEVENSON: What about your family's economic circumstances? You said your dad was a firefighter and your mom was a stay-at-home mom?

RICE: Whenever she didn't have a little one at home, she was working part-time, and then she worked full-time for a while—she was working when I was in grade school. I was a latchkey kid, so she was working at least half the time I was in school. I forgot the question?

STEVENSON: No, you answered perfectly. I was just wondering about your family's economic circumstances growing up.

RICE: We were middle class. Lower-to-middle class. We did fine.

STEVENSON: Did you help contribute to your family's income growing up?

RICE: I got a job at sixteen and have worked ever since, but I didn't have to contribute to that. They paid for a private high school, and I went to parochial school; I think you had to pay a little bit for that. So they had enough money to do that. I did have a job and bought my own things once I turned sixteen—contributing in that I wasn't taking away too much.

STEVENSON: Did you stay in the same home that you were born at growing up, or did you move around?

RICE: We lived in a couple of different places. We had to stay in the city of West Allis because my dad was a firefighter there. We moved when I was about fifteen; I was in the same house when I was little until about fifteen.

STEVENSON: Did you move cities when you were fifteen, or just houses?

[00:04:59]

RICE: Just houses because my dad had to stay in the same city.

STEVENSON: Got it. And do you remember anything specific about your childhood house growing up, maybe any specific smells or scents?

RICE: I don't particularly. As far as things that bothered me, or just smells?

STEVENSON: Just any scents—maybe like a laundry detergent or an air freshener that you associated with the house?

RICE: We didn't have things like that in the house. I don't know how common they were back then, but we were minimalist as far as a lot of smells. I think my mother wore a perfume; I can't think of the name of it, but I think it's still around. And not a lot.

They both smoked. When my mom was pregnant, she smoked, and when I was growing up. I think she stopped when I was in high school.

STEVENSON: You said your dad was a firefighter—do you remember him ever bringing home any scents on his clothing or anything besides the smoke?

RICE: I don't remember any. I think he left everything at work and showered. Anything he wore at work, he left at work, and they washed it. But no, I don't remember any smoke or anything.

STEVENSON: Do you remember the sorts of foods that your family ate growing up?

RICE: Well, typical spaghetti and meatloaf, and my mom tried different things, like she would make a Reuben casserole, I don't know. But we did eat a lot of fresh vegetables, and they were big on al dente—everything wasn't all smushed. My mom was a good cook. We had a lot of variety, a lot of different kinds of food, sometimes ethnic-type food. They were pretty health-conscious. My dad's mom was a juicer, way back. My dad was big on pushing vegetables. So yeah, we ate pretty good for that period, growing up in the '60s, I think we were really healthy.

STEVENSON: You said your parents were very health conscious growing up. Would you consider yourself also health conscious when you were younger?

RICE: Yeah, to a fault, really. I was never the kind of kid even who ate Fritos and Pepsi for lunch. I would always eat the sandwich—and then the Fritos. Obviously, I ate some junk food, but I wouldn't sit and eat a bag of Oreos or anything like that. I was aware, and I know by the time I was in college, I was thinking about it a lot. I would eat three meals a day. I was never an overeater; I've never been overweight. Conscious about exercise—whether or not I always did it, I knew it was something I needed to do. I didn't really do drugs.

Do you want me to say a little bit about now—my adulthood?

[00:08:36]

STEVENSON: Sure, you can dive in now.

RICE: Well, as an adult, I was very conscious, and when I had my son in 1985, I was even concerned about things like—they said, “Give him Tylenol.” I looked, and I said, “Well, there's dyes in in that.” Of course the doctors said, “Well, they're so minuscule.” I considered whether or not I should have him vaccinated. I did. I thought about those kinds of things.

We always ate relatively healthy. Back in—1988, wow, it was a while ago. In 1988, we joined a CSA—community-supported agriculture farm. That was a long time ago; it was the first one in

the Midwest, actually, and we were charter members. That was thirty-plus years ago. Even prior to that, as I was saying, I was thinking about what I was eating, what I was putting in my system. Recently, the last probably decade or so, I've been pretty much all-organic meats, and I eat a lot less meat. Environmental Working Group puts out the ten worst vegetables and fruits as far as pesticides, and I never eat those—I haven't eaten a non-organic strawberry in probably ten years. I just am very conscious about all that stuff. They don't even taste good. I don't even bother because I look and am like, "Oh that's poison," so I just won't have it. I've been, like I said, very, very conscientious about what I eat and how I eat it. I don't eat a lot of barbecued food—stuff on the grill, the burnt stuff—I don't eat that. I don't eat a lot of sausage. Once in a while, but it's not my kind of thing.

STEVENSON: Was this health-conscious attitude that you have part of your community, or did you get that from your parents? Or is that something you found on your own?

RICE: I think I got the basics from my parents, and just enhanced it with my own reading and getting information. I was reading books—like Rachel Carson's *Silent Spring*. I was reading books about the environment and health and all that kind of stuff way back in the '70s.

Me and my mom, we were commenting once in a drugstore. This lady was really upset because they didn't have green toilet paper. If you remember back then, they used to have colored toilet paper, very common: pink, green, blue. The woman said, "I don't know what I'm going to do without it." My mom said to me, "She must have a pretty pathetic life if the most important thing is the color of her toilet paper." She said, "Tell me if I ever get like that." That was even back in the '70s. Talking about things like dyeing green toilet paper, whereas most people just accepted it. Obviously, we didn't buy it—maybe when it first came out, but by then my mom was pretty conscientious about things like that. It's just an undercurrent; it wasn't anything we discussed at length. We didn't sit around the table discussing the environment, but it was an undercurrent. Off-hand, somebody would say, "Oh, that's not good for the environment," or, "Maybe we shouldn't eat that." It wasn't a plan, per se.

[00:12:31]

STEVENSON: Do you think that your family was unique in your community in that way, that you were so careful about what you ate?

RICE: I think somewhat. I think a lot of people were more the meat-and-potatoes kind of people. While we had that, we had a lot of different things; my mom would try different vegetables and different ways of cooking. Even now, I think we're unique to some degree. There's a lot of conscientious people, but there's a lot of people who don't know how to eat right, or don't know about—or choose not to be informed about—what's good for you and what's not. Or the old, "Well, I'm gonna die of something, so I can eat this or smoke this"—cigarettes or whatever. So I think we're relatively unique.

STEVENSON: Jumping back to your childhood and growing up—what was school like for you? That must have been difficult as well, switching schools at fifteen. What was your school experience like?

RICE: Why might it have been difficult?

STEVENSON: You said that you had moved at fifteen—did you continue going to your same school, then?

RICE: Yeah, I went to the same grade school for nine years, kindergarten through eighth. Then I moved when we were in high school, but I went to the same school. Like I said, we were in the same city; I'm right next to Milwaukee. My school was actually in Milwaukee, but I took a bus—from both places, I had to take a bus. I remember saying I wanted to stay at my high school. My mom said that was obviously an option.

STEVENSON: Did you enjoy your high school experience, then?

RICE: I had a good experience in that I was real smart. I'm real smart. I was not popular, per se, but I was invited to everybody's pajama party. I was friends with everyone—I shouldn't say I wasn't popular. I had a lot of friends. I was pretty quiet back then; I guess maybe people would call me shy, but I just was really quiet. I grew out of that in college, became much more assertive and talkative. Though I think I knew my own mind back then, for what that's worth.

STEVENSON: Did you work at all before going to college?

RICE: I was working. I started working at sixteen. I worked at one of those little grocery stores they used to have, kind of like a 7-Eleven; it used to be open when regular stores weren't. If you can believe regular stores were closed. Then I worked in retail at a mall. I did that till I went to college, and then I lived at home. I continued working, while I was in college. I didn't have a straight shot from college to my career, but I was always working somewhat while I was in school, part-time.

[00:16:17]

STEVENSON: Where did you go to college?

RICE: I went to the University of Wisconsin-Milwaukee (UWM).

STEVENSON: Do you want to tell us a little bit about your college experience, what you majored in, how that was?

RICE: Sure, I started out being a nursing major. Back then they didn't do a lot of—well, I don't know that they do it now—career counseling, which I think would have helped because I floundered. I went into nursing, and I didn't want to take chemistry. I don't know if it was organic or inorganic, whichever is the more difficult chemistry. So I switched majors to medical records administration, which doesn't even exist anymore. But that person would run a medical records department, and I ended up having to take chemistry anyway, because I took a lot of medical classes. I did get a degree in that. But I was more thinking along the lines that I wanted to be a medical librarian. I don't know how I got to thinking that that was a good idea. But I did

well in college, I did well, and then I worked for a while, different jobs. I worked on a psych unit and a couple other things I can't remember right now—probably in retail.

I went back for my master's in my late twenties. I got a master's in library science. I graduated when I was about thirty-two, thirty-three? I have 203 credits at UWM—you only need 120 for an undergrad, and my master's was thirty-six. I technically could have gotten through with 156 credits. But because I switched majors a couple of times, that's what happened. I actually have a minor in English "by mistake" because I took so many English credits. It was a circuitous route to become a librarian, but that was a good fit for me. I only wish I would have realized that sooner, but I wouldn't be so well-rounded otherwise.

STEVENSON: Exactly. So, after getting your master's program, you went straight into a medical library job, you said?

RICE: No, no, Actually, I had my son right when I was finishing the last year or so of school. I was with him for a couple of years, till he was almost three. Somehow it was coordinated when he was three and I went to work part-time, and my husband was at home with him during the times I worked. So we didn't have a lot of daycare, which was what we wanted. I didn't want other people to raise him. We were able to figure that out, and I went to work at a college library.

STEVENSON: When did you get married to your husband?

RICE: We got married in 1978. I was twenty-five.

STEVENSON: How did you guys meet?

[00:19:42]

RICE: We met at work. That was in one of my breaks from school, switching around. We worked at a residential treatment center for autistic—before people talked about autism—schizophrenic, psychotic kids. We bonded there and then got married a couple years after we met. A pretty good experience for anybody, if they want to find out what they're made of. Work with kids that are—some of them were acting out. I learned a lot. Nothing much fazes me now. It's a good experience.

STEVENSON: Jumping now into getting into your chemical sensitivity—you referred to it as MCS (Multiple Chemical Sensitivity), I noted from your pre-interview, is that correct?

RICE: My diagnosis?

STEVENSON: Yes.

RICE: Yeah, my diagnosis is multiple chemical sensitivities. Yes.

STEVENSON: When was the first indication that you had the sensitivity?

RICE: It was within the week of having carbon monoxide poisoning.

STEVENSON: Can you describe for us that incident?

RICE: Describe the symptoms?

STEVENSON: The carbon monoxide poisoning, first of all.

RICE: I was at a movie theater. It was the first day they turned the heat on. It was either human error, or the vent fell, in that everything—what ended up being fumes of a sort—everything backed up into the theater. I can't think of what I'm trying to say. The furnace was on, and the vent was closed. So everything that was being, you know, off-gassed—I can't think of the word. Anyways, they can figure it out. The carbon monoxide that formed went into the theater, and my husband and I were both there. We were watching the movie, and a guy walked down the aisle and started talking to us. I moved my head, and I knew right away something was wrong, because I felt really woozy, and my head felt like it was ten times its normal size. Coincidentally we were watching the movie *Lost in Translation*, which is sort of funny. Quirky title for what's happening to us. But anyway, we'd been in there probably close to a half an hour. We left the theater—I don't know what he was saying, but I'm sure he was saying to leave the theater. So, we did, and we went outside.

I felt really woozy, and I felt really lightheaded. I felt a little nauseous and a little confused—spacey. There was a nearby emergency room a few blocks away, so we went there and were treated for carbon monoxide poisoning, which is four hours of pure oxygen—that's the protocol. Sadly, they discharged me while I was still symptomatic. They didn't ask me if I was symptomatic; they just said, “Are you ready to go home?” I said, “Sure.” But I assumed since they let me go that I would just sleep it off. I didn't. I woke up the next morning, and I still felt a little woozy. I thought, “Well, maybe it's going to take time.” Coincidentally, we went shopping for lighting fixtures, and we went to a lighting store, and I had to sit down. The lights were bothering me. I said to my husband, “Take me to St. Luke's (Medical Center), to the emergency room.” I went there, and I was evaluated by the hyperbaric medicine MD. He said, “You still have the symptoms.” My CO blood level had gone down from nineteen to one, but I still had the symptoms. He said, “You're a candidate.” I spent three-and-a-half hours in the hyperbaric chamber that night. And then I went back, I think, five more times. It's funny—again they say, “Are you ready? Do you think you're done having these treatments?” I said, “Well, I don't know. I'm sort of confused. How would I know? I'm lightheaded.” I make jokes now, but it was traumatic, to say the least.

While I was doing that, I was still going to work. In the first couple weeks after, I worked full time—I probably missed more than half of that time, due to having the treatments and then being out of it—not being able to function. The lighting was the first thing I noticed. Then I went out and had a beer, and I was out with people, and that was a bad mistake. I don't know if I was noticing anything at that point; I know that the beer made me feel yucky. That may have just been because I was woozy to begin with. I don't know if the beer was the best idea, but I wasn't told I couldn't.

At work, I started noticing fragrances of people. That was my first indication that maybe something was going on with that, though I had no idea why it was happening. I didn't put two and two together. I just thought it was maybe because I was woozy, and so I was noticing things more. You know, you don't think clearly for a while until your head clears. I don't know if it ever has cleared, to be honest. The carbon monoxide does stay in your heart and your brain if it's not removed permanently out of your system, which mine wasn't because I didn't get the right protocol right away.

It's really sad because I live about six blocks from a hospital, which is where I went the second day, and the first hospital as well as this one did have hyperbaric chambers—the two main ones in town that have them. I'm literally six blocks away. I could have gone there on my own. But like I said, I didn't know the protocol, so I just went with what they said. But to get back to your question—within the week, they had permanent markers, stuff like that, at work that were bothering me. That was the other thing that I noticed.

[00:26:42]

STEVENSON: Just so I'm clear, you were working at the library during this time, correct?

RICE: Yes.

STEVENSON: Jumping back a bit more to the first incident of the carbon monoxide poisoning. You said your husband went to the movie theater with you? Did he experience any of these symptoms?

[00:27:02]

RICE: He didn't experience any symptoms, but his CO level was checked, and his was fifteen, which is high because you're supposed to be about zero or one. But it all depends on the person, how they're metabolizing it, or whatever. Some people's level could be higher, and they might not feel symptoms, and some could be lower. I think I have a pretty fast metabolism. Not that his is slow—but I think that's why I felt it right away. That's kind of what I assumed. He also went for the four hours of oxygen with me, and then he left—we left together, I guess. Actually, he left a little early; I don't know why. He didn't feel anything still. Sadly, he did have a major heart attack nine years ago. He really didn't have risk factors other than he had controlled high blood pressure, but he's in shape and he eats well; he's not overweight. The information we have now is that carbon monoxide can cause atherosclerosis, which can, of course, affect your heart. That is where it stays, if it's not all taken out—it stays in your heart and your brain and can cause damage along the line.

I don't think they know exactly the timing of everything, but the doctors were really shocked that he had had that. Based on his history, he shouldn't have had a heart attack. When we're outside, he does notice dryer sheets and the like. He doesn't have the same reactions; he has a little bit of a reaction, but he doesn't notice when food smells bad, or whatever. So it may be partly his sense of smell, and partly his sensitivity is not anywhere near mine, but he does notice. Things like dryer sheets are one of both of our triggers. He used to like the smell of tar, and now he doesn't.

You know when they put tar on the road. Well thank god, now he doesn't. But that's how he knows that he's been affected.

STEVENSON: Did you have any other health issues before the carbon monoxide poisoning?

RICE: I've had a few over the years. A couple of autoimmune-related skin conditions and other conditions. I've always been relatively healthy, but I've had stuff wrong with me. I don't have my health history in front of me. It's pretty involved; I wasn't going to give you the whole thing, but I had anemia and things like that. I was diagnosed with Crohn's disease—that really wasn't what I had, but they couldn't figure it out. They just rule everything else out. I had lost a lot of weight in a very short time; I still think it might have been a parasite or severe food poisoning. But I was relatively healthy, and in my forties I was really healthy. When I got the carbon monoxide poisoning, I was just fifty. That was a kick in the head, because that was probably my best decade.

I didn't have anything catastrophic before then. The only allergy I ever had—because people relate it to allergies, which it isn't—but I had some issues with hay fever in my twenties. Since then, no. I don't have any allergies to pet dander or food or pollen or anything. I might have a grass allergy—it's hard to say—but nothing that impacts me in any great way. Which is always confusing to people because they say, "Oh, you must be allergic." I said, "No, you can give me a cat. I have two cats."

STEVENSON: You said when you had the carbon monoxide poisoning, you had to take time off work? How was the library? What was their reaction when you started having these symptoms?

[00:31:50]

RICE: The person who was my boss—the director of the library—had known me for close to fifteen years, so she trusted that what I was saying was true. Because people might not believe what was going on, but she was really understanding. Sadly, she left; she retired early. Then we had a new person who was understanding in that she didn't question me being away. But she also wasn't supportive when I started smelling things there, even though she had allergic reactions to things and also really didn't do well with air conditioning. So she understood having reactions, but, being new, she wanted to not rock the boat with an employee who was complaining. Because there were smells there—that was what ended up triggering me, and I had to leave there. But yes, my boss was supportive at first; the powers that be were not. I never talked to them directly, but their ways of dealing with me were pretty poor.

STEVENSON: Do you mind just reminding us of the triggers that bothered you in the library or the scents or smells?

RICE: The things that bothered me that happen in libraries or other places were the markers and any kind of glues or adhesives. They did one day put some sort of glue on the front doors, and it permeated the hall all the way down to the library. I got sick. I did go to the workers' comp clinic; it was decided that yes, indeed I was being affected. The doctor there for some reason

knew about chemical sensitivities; this was in 2004 and many mainstream MDs (medical doctors) weren't aware of MCS. So I had to go to another part of the building—I think I went to the computer center—and did work for a few days. I couldn't be on the reference desk, which is one of my jobs, because I was a reference librarian. I had to go to another part of the building and hook into the network there and work. There's probably at least a week or two that I was gone from the library itself, because glues and solvents and things like that are one of my triggers. That happened. Once someone actually mixed ammonia and bleach somewhere in the building, and everybody got sick, because everybody's eyes were burning—yeah, that's not good.

When they did the glues and solvents, it's funny because people were having other kinds of reactions, like sneezing and headaches, but none of them attributed it to that. People just say, “Oh well, it must be because I'm tired.” Or, “It must be because it's pollen,” or something. People don't necessarily think it could possibly be the same thing that's affecting Jackie. “Maybe we're getting sick for the same reason that she is, there's a toxin running down the hall.” Other people noticed it. Oftentimes people notice things, but they don't necessarily react—or if they react, they blame it on something else.

STEVENSON: Did you feel like you had to speak up in the workplace to say, “Hey, this is what is actually causing it?”

RICE: I mentioned it, but I didn't push it, because I had to look out for myself and make sure I got the care I needed. They sent me right away to the workers' comp person to be evaluated, because they knew my history, and did want to do right by me in that way. No skin off their nose that they sent me there. They did check out that I was having a reaction. I never question when I have a reaction; there have been times that I've had reactions, where I didn't even “smell” anything, because it isn't the smell that causes it. It's the toxin itself; the smell is just, you know it's there. I've had times, especially a couple times when I worked at the library—I got really hoarse. I actually lost my voice, and it wasn't from talking. I was working at the reference desk. I started talking to someone, and I said, “Oh my gosh, I'm losing my voice.” So there was something present that I didn't know. My voice came back after I left, so there's something present that I wasn't aware of that was causing me to be symptomatic.

STEVENSON: I know that you knew that you had these reactions before to chemicals and toxins. But was this the first time that the doctor from the workers' comp had labeled it as MCS? Or had you seen any other doctors before which had given that diagnosis?

[00: 37:27]

RICE: It was probably right around the same, unless—timeline's confusing—I was diagnosed with chemical sensitivities, and sadly, the doctor just retired. I was going to go back and see him. I was diagnosed sometime in late 2004. This must have been right around the same time that I saw the workers' comp doctor because I had heard of it. Because I had it. It's funny, I was trying to remember if I even knew—I must have known something about it before then, but not much. It's been integral in a way to my life—how I live my life.

STEVENSON: Had you done any online research or anything before seeing the doctors?

RICE: Before seeing the doctors, probably. I have to say that my memory of it of that time isn't as good as other times in my life, time-wise and situations, and I think it was partly because I was "woozy," for lack of a better word. Sometimes I felt like my brain was sticking to my inside of my head. Like when I would shake it. Even now when I shake my head real fast, I feel sick. It was almost like there was a certain—not cloudiness, but something that was preventing me from thinking clearly. Based on what was happening with me then, I think I'm better now. I know I'm better now. There was a lot of brain fog and things like that; I should have documented some of it a little better. I did document a lot of it, but that part was very all over the place in my memory.

STEVENSON: I mean, this is perfect, the account you're giving us. You're doing great. Did you have a community during this time that you reached out to? Was your husband supportive during this time?

RICE: Yeah, he's always been supportive. He's not one of those weird guys. I just had this surgery and was reading online about a woman (who had a) parathyroidectomy—which, if you have hyperparathyroidism, you can have brain fog and also be fatigued. I have to say that it's helped me. Just as an aside, someone was saying how they hoped that he (her husband) helped out and I thought, "Why wouldn't he? What the heck?" What, are we living in the '50s? He's an equal; we're equal partners in all this, and I don't ascribe, you know—I was a feminist way back in the day in that men and women are equal and don't put up with crap from men. My husband doesn't even say stuff like chick flicks. I mean, that would be so foreign to me. I always think he's very much like a woman in that he's just regular, like, can talk to him about anything and not feel like, "Oh, boy, he's going to judge me like a guy." He's just like a regular, he's a person, he's not like, "Oh, he's a guy." You know what I mean? Maybe that doesn't sound right. But anyway, long story short—yes, he is supportive.

He pretty much understands because he has some of the same things, so sometimes we'll be around people that were smoking, or were wearing perfumes; he doesn't always notice and sometimes he comes home and he smells bad. Everything goes in the wash with vinegar. I'll say, "You'll have to strip down," and he does. He doesn't ever question that I'm having a reaction, which is really good. I don't think he would anyway, even if he didn't know about it, hadn't from some firsthand experience. I still don't think he would. I wouldn't be able to live with somebody who was questioning me or not being supportive—they would be out. I don't put up with crap, in general. I wouldn't put up with that kind of crap. With my friends, it's funny, most of them have been pretty supportive. Some actually started making changes in their lives. But anyway, going off on a tangent.

[00:43:01]

STEVENSON: You said they're making changes in their life? Is that something that you've asked of them? Or just something that they initiated (crosstalk)—

RICE: Well, I told them that I can't be around perfume. I mean, I can't. A friend of mine who wore it doesn't wear it around me. I said, "Well, and for yourself as well." Some people you can say that to, no problem. Most of my friends, I can say that to. A lot of my friends are pretty

earthy like me—can't be bothered. I wear a little makeup sometimes, but I'm not high maintenance. A lot of my friends aren't either. We all look presentable; we all look good. Some of them even look fantastic. Everybody dresses really well, and looks really well—we're not walking around in big t-shirts and sweatpants all the time. That was really an aside there, but a lot of them are not high maintenance. Like, "I've got to get the newest eyeliner, and I've got to get this, that, or the other." We're more about eating healthy, getting good sleep, and all that kind of stuff. That's how I stay healthy or look healthy—just do that stuff. I was always like that. When I went to school, it's like, "How much time do I spend—oh, I can sleep in? Well, I'll do that instead of putting on makeup." I've always been kind of basic in that area.

A friend of mine just went to New York with me and we visited another friend, and the friend in New York stopped using dryer sheets based on what I said. Now, when I was there, I still smelled something, and I went in her basement when she wasn't around, and she was using Tide. Ooh, that's bad stuff. I didn't say anything, but all my clothes came back that I didn't leave in my suitcase with it (the Tide scent), because it's all in the air. You don't even realize it's landed on my clothes. I was in a bedroom all by myself, but the stuff that was in her closet or whatever just came on to my clothes. It's just really sad.

But the other woman I went there with said that she got fragrance-free lotion and wasn't going to wear any perfume or anything, said, "I don't wear it much. I'm not wearing anything." She said, "I'm into being kind to people for Lent" or something. So whatever works. That was really nice of her because she didn't smell. She didn't bring any fragrances. I thought that's really kind.

A couple people have been really rude about it that weren't my "friends" but people I knew or work people. I had a part-time job after I left the library, for a nonprofit, and I was in the bathroom. One woman was cleaning the bathroom—one of the volunteers—and I said, "Oh, don't spray in there until I go in." She had Lysol or something. And she sprayed it in my face. Like two feet away, and she didn't spray a lot, but she just sprayed, and there was a little giggle. I couldn't believe it. It's not funny. They knew that I'd mentioned it in passing that I didn't do well with stuff. Nobody really changed their habits because of me, but luckily it wasn't a place where there was a lot of that. But I ended up having to leave there because they put sealants on the floor in the basement. It all came up through the vents. That was in November, so I couldn't open the windows, and it didn't help anyway. I went off on a tangent, sorry.

STEVENSON: I know from your pre-interview questions, you say if you go out a lot and do things, do you ever find yourself having to leave certain places?

[00:47:38]

RICE: I've had to leave people's homes. One person was supposed to be a meditation group. I started getting sick. She kept saying, "Oh, it's the candles in the kitchen." I said, "Could be, but they have the door closed." What they had was they had one of those fire logs. You know, it's already a log, and you light it up? Yeah. That gives off toxins. So that was it. I said, "I'm pretty sure it's that," and she said, "No, I don't think so." It's like, "Well, I'm pretty sure, but anyway, I've got to go." That was a disappointment.

I like to sometimes go to secondhand shops. I'm pretty much not able to anymore, because of the smell, the clothes will smell—the Goodwill here sprays their clothes with Febreze; that's how they clean them to put them on the floor. That's bad. Any place that has secondhand stuff, maybe also because some stuff is moldy. Then people come in. So those I'm not able to go to as much anymore, or hardly at all. I've had to move obviously in movie theaters; I've had to move when I've gone to see plays. I said, "I need to sit somewhere else," and they accommodate it.

If people are highly fragranced, I do bring a little fabric mask. I don't have this for my nose and mouth—I don't have one of those big contraptions, though I'm probably going to have to invest in one. I don't know which one, and I have kind of a small head and a small face. Not a tiny head; it's normal size, it's not huge. I want to find one, but a lot of them are form fitting, and I don't know what size to get and all that. You can't really go try them on, and I don't know where there's a store. A lot of people buy them online. But I'm going to end up having to do that.

Yeah, just some public places I've just had to walk out of for a variety of reasons. Hospitals, those are bad. Just had a terrible experience at a hospital. Supposedly the staff is fragrance-free. Well, I had that surgery I mentioned, and I had to jump through a lot of hoops and talk to the director of operations, and I don't mean of the operating room, that wasn't the title—manager of the operating room or whatever. To make sure that I wasn't going to have issues with fragrance, you know, dryer sheets. They said they all clean them there; they wash all the clothes there and they don't use dryer sheets or scented laundry detergent. So I said, "Okay, none of the staff can." You would think that would be a given, that they wouldn't wear perfume or lotions in there. But it's not a given. There is a "guideline" about not wearing fragrance. I had to make sure that they didn't use any super strong stuff right before I came in.

One thing that was a problem, which I didn't see coming, was they put a plastic mask on my mouth and nose, and it kind of freaked me out because the smell was really making me sick. But I wasn't sure why they were doing it. I didn't know if they were going to leave it on. What they were doing there was trying to get me to get oxygen in my system so my oxygen levels are high enough. I didn't know that. Then they finally explained it to me as I'm talking through it to them. They took it off. And I said, "Oh, okay, I thought that this was going to be on, and I was going to say you can't do surgery if you have to leave this on." So someone else mentioned that. From now on, they would tell people why they were doing it beforehand. I said that's a good idea. Because I was like, "You're giving me my sedation through an IV, right? You're not going to do the old-fashioned gas."

You know, you're lying there, and you don't know what they're doing. That was the problem I didn't see coming, because I did have to inhale that plastic. And that was bad. It's just yucky. That's all it is, is plastic. My point being, sometimes I have to go to great lengths to make sure that the environment is safe for me. I try to go about my life pretty simply and not complicated. I will not make a big deal. I don't mean it that way. If I can avoid, or make a plan ahead of time, or tell people ahead of time—I try to do pre-planning, but that doesn't always work. I realize sometimes I don't mention it to somebody about the perfume or getting in a car, and there's people with perfume. Or a friend of mine was going to have a party, whatever kind of Tupperware, like one of those parties, and I didn't go. I said, I'm not going because I don't know. I'm not going to ask her to tell people they can't wear fragrance. So I'd like to, but.

[00:53:30]

STEVENSON: Do you consider yourself your own advocate for MCS, or maybe an advocate for MCS people in general, having to occasionally ask people to make accommodations?

RICE: I definitely, definitely do and I am trying to put out feelers every which place I go—within reason. I don't know if I should bring up one thing that I've done in the last two years. Two years ago, I had an issue in a bathroom in a restaurant, they had an air freshener that was those wall-mounted ones. I had a very severe reaction; it must have been fresh, with all the scents pumping out majorly. I was in there and out of there really quickly. Then I was at a hospital for an appointment, and I went into one of the bathrooms, and the same thing happened. I literally had to hold on to the sink because of the potency of the air freshener spurting out. I did say something to someone in the bathroom with me. I said, “So do you notice that smell?” She goes, “Oh yes, gross, isn't it?” I said, “Just checking,” because other people don't like it, but they don't say anything.

Anyways, I complained and went through several different departments before I finally got to the right place and was able to have them remove an air freshener from one of the bathrooms so that I could use that one. It's really funny because they did, and then it came back. I was really-- What's happening? So I got a hold of somebody finally. And, they had a service doing it. Now this person apparently didn't even know that. So they had maintenance take it off, but then a service came and put in a new one. You would think they would sort of know where and how those are being mounted and by whom—no. So I went in and complained a little higher up to administration, and a woman comes in and I said, “Oh, you're wearing perfume. Great.” So we were not best friends from then on. I told her about what has happened. She said, “Oh, well, we've got to make sure that that stays off,” and “I understand that.” And I said, “Well, I'd really like to talk about fragrance issues in the hospital in general.” And she's like, “Well, this is most important that we need to make sure that that one bathroom is safe for you.” And I said, “Right.” But she just really put me off as far as talking about any other, you know, the use of fragrance in hospitals in general. She didn't want to talk about it, and they don't want to talk about it. I think it was sometime last year, probably last fall, probably October, where they removed it. It's been gone since then, so I can use that one bathroom. That's good.

You get a lot of when you complain about it, like I did from her. I've gotten it other places where I just sort of said it like at a restaurant, I'll say, “You have this air mounted (air freshener in the) restroom.” I don't think I followed up, but I should have; it was a health food restaurant. I said, “You know, those are really toxic and really unhealthy.” And he said, “We have those up for the comfort of our customers.” I said, “And I would be a customer.”

[00:57:24]

They don't always want to know. There's a lot of that, “Oh well, other people complain.” What I hear is, so many people are complaining about the odors and bathrooms that we have to put them up. I'm thinking a lot of people don't say anything. That's why I'm sort of this voice in the desert sometimes, because I'm one of the few people who say things, I think, with MCS, because they'll

either just run out and like, “Okay, fine, I’m not going to say anything,” or they don’t want to rock the boat, or they don’t know how to address it. I just think that we’re doing ourselves a disservice—everybody who’s bothered, whether they have chemical sensitivities or not. You don’t have to have chemical sensitivities to be bothered by a new carpet. You know? Everybody notices it. Some people think, “Eh I don’t want to be in this.” I want to tell you this, if we put somebody in a newly painted, newly carpeted room for a few hours, eventually, most people would feel like crap. Oops, I said crap on the tape.

My point is that sometimes it’s just how strong the toxin is, or how concentrated and how long you have to be with it. Eventually most people would be bothered. If you lock somebody in the room with whatever it might be, with an air freshener on them for maybe an hour. It’s not fresh. It bothers me because some of these things are actually carcinogenic, and air fresheners trigger asthma, fragrances trigger migraines. It’s just not talked about, and it really needs to be because there are people who probably would have fewer migraines if they weren’t exposed, or if they knew that that was one of the triggers. I’ve talked to people, and I say that, because I’ve talked to people with migraines who have said that that’s a trigger. I know that air fresheners can be a trigger for asthma. I feel bad for little kids who will go in there and have asthma, and then have a reaction because that’s not right, especially in the hospital, for example.

I can tell you that this is good news The Wisconsin Department of Natural Resources (WDNR)—they oversee the rest stops. They did a survey, and because of the responses, they took out all the wall-mounted air fresheners and all the scented soaps from their bathrooms at the rest stops in the entire state. That’s pretty good. And they did it based on a survey of regular people. I thought that was interesting, I wonder if they would do more surveys because supposedly a third of us have issues with fragrance—at the very least, to see if people really do want all these smells in their lives. I had to leave a hotel; I was sitting in the bar where I’ve sat before, and it’s kind of a lounge-y area where you can still drink, this bar and then this lounge-y area—and I had to leave because they were spewing scented air. Now they’re doing cinnamon and grapefruits and all these things, which are all synthetic chemicals. I got sick and I went up and told them and they gave me somebody’s card, and I haven’t contacted him. That’s been a growing issue. They’re scenting airplane bathrooms, they’re scenting train stations. The stuff I’m reading about, it’s ubiquitous. I feel like it’s like a train that’s on a track, and it’s running out of control. Because it seems like they’re putting out more scents. There’s a new razor for women—the handle is scented. Yeah, that makes no sense. That’s a joke. That makes no sense at all that they would have a scented razor. It boggles my mind.

STEVENSON: I know your husband has sensitivities as well, and you’ve mentioned people with migraines, but do you know anyone else who has been diagnosed with MCS?

[01:02:18]

RICE: No, I don’t.

STEVENSON: Do you have any Facebook groups or anything that you’ve—?

RICE: Yeah, there's one called Creation of a Fragrance-Free Environment (COFFEE). The other one is multiple chemical sensitivity support type group. I think there's a couple of them. So I do go on there, but there's a lot of complaining to be honest. And I don't find that very helpful. You know, there's a lot of venting. I know that that can be helpful, but sometimes you have to go through a lot of those to get to something that's helpful. I actually take it back, I did meet a woman who actually wrote a book. I think it's a book about her sensitivities. She lives about forty-five minutes, an hour from me. I tried to hook up with her a couple more times, but she's got a lot going on. It would be nice to have people to hang out with that had this, because then you wouldn't have to explain why you can't be in that book club or why you can't sit next to that person in the book club because they reek. So yeah, I don't know of anybody. I know there are people out there. Because supposedly there's ten—I don't know—twenty million people that have been, or more? Maybe you guys know. It's getting bigger, but people who've been diagnosed, and the people who self-diagnose is even bigger, obviously. There's people here, but I don't know where they are.

STEVENSON: I know living with MCS can be sometimes isolating and difficult, constantly having to advocate for yourself. Have you ever received any form of mental health counseling, either formally or informally, to cope with this?

RICE: Well, I am seeing a therapist now. I have seen therapists a couple of times in my life. And I'm seeing one I've been seeing for about five or six years, I think. And she helps people with chronic illnesses, which this is sort of dealing with something that's chronic, which I mean, I don't think I'm going to get rid of it. I can build my system up by avoidance. But then when I have a trigger—usually luckily I don't collapse in a heap or anything. I just feel lousy. My general reaction is, I have trouble swallowing. I get a lot of postnasal drip. I will get lightheaded and dizzy and nauseous. Those are what happens to me. Everybody else is different. A lot of people have hundreds of symptoms, but those are my main ones. So she's helping me with just coping with having a chronic condition. So yes, to your question—yes, and I think it is a chronic condition. It's not anything that will go away overnight or anytime soon. I don't know if it'll ever go away; I might get a lot better dealing with the toxins. But the more that are out there, the less likely I am to bounce back.

Right now, my neighbors and I—I need to go talk to them. They've been here for two years. They use really potent dryer sheets, like cherry-flavored Snuggle; it's really, really strong. And dryer sheets—my husband and I, whoa, that'll knock us for a loop. So I can't be outside when they're doing it. And I have this really cute backyard and I can't go back there to hang out. We have a cute gazebo, and obviously a place to sit in the gazebo, and I can't spend any time out there with the dryer sheets. We have a garden; I don't want to eat anything in the garden, because that stuff drops. It's everywhere. I have to go talk to them, because this will be the third summer that I won't be able to spend time outside. We paid off our house; we want to spend time in our yard. They're right next to each other. And it wouldn't matter if there was a fence, because it still crosses over. There's no regulations on those kinds of emissions, even though they are being emitted into the air, and they are toxic. So I have to appeal to their kind hearts. I wouldn't do it the first year because they just moved in, in the second year—but now, I want to cry when I think about how I can't go outside and just be free of it.

So I walk in my neighborhood, and I have to bring a mask, and I still can smell it. But I would say I've never walked outside in the last few years where I haven't smelled it at least once—people's dryer sheets—and that's not my neighbor. That's just in the neighborhood. So I'm going to have to advocate for myself and my husband. And I'm also going to bring them little dryer balls, and I'm going to bring them—if I can find it—non-fragrance dryer sheets. I don't know that those exist, but they say no scents. But having no scent is different than no fragrance. The no-fragrances—sometimes they can sneak them in.

I can't live my life. I can't. I like to be home. I like to go out, but I like to be home in the summer and enjoy. We have a prairie in the front and the back. We removed all the grass, and we have native plants and flowers. In the back, it's like a flower bed, and it's gorgeous. Bird bath—we get hummingbirds just coming in. We don't even have to put out sugar because we have a pretty nice natural habitat for them. We got an opossum wandering through the other day. I live in the city; I actually live on a busy street—not major busy—there's no trucks, but it's a busy street. That was a bad move when we moved here twenty-five years ago. I don't know what I was thinking. We keep the front doors closed. Now I have to keep the side door closed because the dryer sheets, the side windows. When I open anywhere, I have to make sure that they're not coming in. Sometimes the people on the other side use them. That's very isolating as well. I don't want to be inside my house all the time. Yeah, it can be very isolating.

[01:09:43]

STEVENSON: Besides your therapist, do you have any relationship with any of the other doctors—I know you said you were going to see one that just retired. But is there any other primary care specialist that you see?

RICE: No, I don't think there's anything they can do for me. There is nothing they can do for me. People say they go to an allergist and the other—maybe to get a diagnosis, because some will diagnose that. I don't know if I should mention the guy, his name is George Kroker, and he is the one who diagnosed me. He studied with Theron Randolph, who was considered the father of environmental medicine. So he knew his stuff. Randolph was the first person to identify someone with chemical sensitivities in the '50s. So the guy I went to knew his stuff. I was so lucky he's only three-and-a-half hours from here by car; I was really lucky that I had somebody in my neighborhood pretty much that I could go to.

I was going almost every year, and then I didn't go for several years, and he did use some of those antigen-type drops that you could use to kind of lower your reaction when you were having one. I did use those sometimes, and they did help. But I haven't had those in years, because I usually just try to leave if at all possible. I just found a new primary type care physician. I mentioned it, and he knows someone with chemical sensitivity. So he was all about, "Sure, I got it." He got it right away. My other doctor also was a regular doctor, but he did traditional Chinese medicine as well. He knew about it, and he was trying to help me with acupuncture and other things. When I went to talk about having the (parathyroidectomy) surgery, they were fine with it. A lot of people say that people laugh at them and do all this stuff and doctors just poo-poo them or tell them they're stupid. I've never had that experience. But if I did, I would tell the doctor off and leave, but apparently there are doctors out there like that.

[01:12:10]

I am trying to think of a medical professional who was rude to me about my MCS and I can't think of one. My therapist, she was like, okay, she'd heard of it. I don't think she has any other patients with it, but she got it right away and never questioned me. I don't really have people question me. Maybe strangers would, but people who know me? I have had to go to a number of different doctors because of health issues. I had some vascular issues, and I had aneurysms under my pancreas. I'll just say that. And it was very rare. I had to have major surgery. I'll just say that I had to see several physicians for that. I mentioned it—“don't wear perfume”—or when I went to have testing I've called ahead and said. If I'm having a scan or something, if I'm having an ultrasound next week, it's like, “No fragrance, please.”

I did have an ultrasound once—it wasn't that long ago, a couple years—the tech was in the room with me. She was learning, and the more experienced tech was watching from another room. I should have said, “I can't be by you. You have dryer sheet smell.” Instead I had a mask on, and I told her I had a mask on, but what happens sometimes when you have a reaction or are being affected, you don't think clearly. As in, I should have just said, “Get out, get me somebody else,” in a nice way. But sometimes you don't. You don't use your best sense. You just are confused and lightheaded or woozy, and you don't think, “I have to deal with this.” We do get the fight-or-flight response. When I've been exposed to a great deal of something, I might get agitated and run, which is kind of weird. But usually as I'm running out, I'm like, “I'm having a reaction! I'll be back if I can!” Like I said, sometimes you're not thinking clearly because you get a little confused or woozy, or I do. So that can be a problem. I just had an incident with my—do you want me to talk about incidents?

[01:14:52]

STEVENSON: Yeah, sure, definitely.

RICE: Okay, let's try to be real brief. When I had the surgery, they kept me overnight. They woke me up every two hours, though they might as well not have. I felt crappier the day after than I did the day of, but I'm healing really well, so that's good. My husband came in—long story short, he's fine. But he came in and he sat down and he fainted—passed out in the chair in my room. He was unresponsive in that I'd call his name, and he didn't see. So I was freaking out, pushing my call button, and yelling “Emergency!” Well, long story short, I had to be thrown out of my bed. They put him in my bed and then ended up taking him to the crash team; they end up taking him to the ER. Like I said, he had had a major heart attack nine years ago. So they had a heart monitor. That night they did electrodes on his heart and EKG, right? I'm home trying to recuperate on my own. It was just sad. But anyway, I came back the next day, and they came in, and they're going to take off the—when I called, they said, “We're putting the electrodes on his head, and it's kind of stinky,” which they volunteered. I was like, “Oh well, I can't come there anyway, because I'm at home, trying to sleep.” So he's all by himself with my son kind of there—anyway, so they said it was kind of stinky. I was like, “Oh, that's horrible.” Blah, blah, blah, didn't really register. So the next day I come in. They're going to take them off, and they came in there, and they're going to use acetone. I don't know if you're familiar, but it's the stuff

in nail polish. It's pretty toxic. I said to them, "Oh, are you going to put a mask on him or something?" The two techs looked at me, you know, rolled their eyes like, "Oh, brother, she's overreacting." I put a mask on him and got a whiff of it before I left and ended up in the hall, standing there—literally someone was using a magic marker, a woman walked by with perfume, and another woman walked by wiping the hand sanitizer. I was leaning up against the wall, saying things like, "I'm not doing well." I still had my hospital ID bracelet on from before. I said, "I just had surgery, I don't think I should be collapsing over here." They literally ignored me. It was horrible. And I was worried about my husband, because acetone can cause heart palpitations, and I just need to mention he's being monitored for heart issues, and that would be a bad thing.

[01:17:47]

There was a disconnect in what they were doing to my husband and what was going on with him. Anyway, you shouldn't put it on anyone without giving them a mask. And they should have been wearing masks. It's like people being outside with Roundup and not wearing masks. Or yesterday when I went to the co-op, and they were outside varnishing without masks on—some wooden fence—, and I walked by, and I had to cover my mouth. I thought, Oh, they must be using a really low—no, it was really smelly. I almost said, "Why aren't you wearing masks?" But I didn't. And I should've just because you should just say something every time you see something, people doing things that—I mean they should have been (wearing masks); it was very strong-smelling varnish.

Anyway, I went down to Patient Relations, and somebody called the nursing manager, and I told her all my problems with what had happened with my husband in the room. I was concerned that somebody needed to help him get dressed, because he's been lying immobile for a day. She was very supportive, though, I don't know how far that's going to go. I did write her a note and tell her I had some other things I want to discuss with her. I'm going to talk to Patient Relations. This is speaking about advocating—I'm going to talk to Patient Relations about my entire experience there. Because there were other things that didn't relate to chemicals, but there were some that did.

And also the fragrances—I had to walk through the ER to leave the building, and I got a friend to pick me up after my husband went to ER. If you're not sick before, you'll be sick after, because the emergency room wreaked of every kind of fragrance known to man: Dryer sheets, Febreze, perfume, cologne, lotions. Pretty much on the patients, probably waiting. But it was—I won't use the word, but it begins with cluster. It was absolutely horrendous. I walked to the outer part by the transporters, and apparently all the transporters—whether they're picking up your car, or pushing you through in a cart—there's no fragrance policy. They really smelled. I had to cover my mouth and nose when somebody was pushing me from—I think I was in a wheelchair on the way out. Anyway, it was pretty bad. So there's no—I mean, these are hospitals.

There's an article that I read; I won't read it to you, but it was about how artificial fragrances have no place in a hospital. There's actually a hospital I know in Australia that is for people who are chemically sensitive or want to be in a chemical-free environment. So it can be done. I'm not even saying that should be done, but maybe just not have artificial fragrances in hospitals. It's an

idea whose time has come. I told some people I was going to blow the lid off this fragrance and hospitals thing.

When are people with chemical sensitivities going to get some celebrity who has them? Probably not anytime soon, because if someone has chemical sensitivities, that means—say they're a performer—they have issues with makeup, or issues with foam being put on their face. I mean, I think about all those people in those Avengers movies and how many things they probably have had to deal with. So I am assuming that very few. I know people obviously have them because they've been exposed to many things. Many performers have been, whether it's makeup, or polish, or whatever. But I'm assuming they won't come forward because it would affect their getting jobs. And we have to find somebody who's not a performer celebrity. And Oprah's taken. She already has enough causes.

[01:22:12]

STEVENSON: Yeah. What do you think are some of the next steps besides involving a famous figure, that society could take to change our relationships with how we see chemicals?

RICE: In society?

STEVENSON: Well, even people without MCS, like what steps could we be taking?

RICE: Well, I really think it's a public health issue. And I think public health entities, departments, should get involved in this and be providing information to people about things like dryer sheets, about things like perfume, and the toxicity. They don't have a vested interest in the perfume industry or any consumer products. So I'm curious why they haven't gotten involved—this will benefit everyone. Right? Not only you, but everyone else. So isn't that a public health issue? I don't know. I was thinking of personally trying to go and talk to somebody about that.

I do things like I post on social media. I don't have a lot of followers on Twitter, so nobody's really seeing it, but I'm trying, and so I do a little bit of that. I don't know, because a lot of people with chemical sensitivities tend to not go anywhere, from what I'm reading. Now, I'm not that affected, and I'm not bothered by a lot of other things that apparently some are. I was reading once that carbon monoxide poisoning is a very common cause of chemical sensitivities. Mine was acute carbon monoxide poisoning. I was seriously poisoned. I mean, in another hour, we'd have all been dead kind of thing. I forgot what I was going to say.

STEVENSON: That's perfect.

RICE: Oh. It's a certain kind of poisoning in that, they're thinking that—I wonder sometimes that because I'm not affected by all this other stuff that people apparently are, when people say, “Well, what do you have issues with?” And I say, “Anything that's toxic in any way, I will react to small amounts.” If it's not toxic, I won't react. Like I was at a friend's and I walked in, I said, “There's gas, you need to call the gas company.” She did. There were three leaks and two little kids, and nobody had noticed it. I was glad I did.

But actually, that was the second time—I was at my sister's with my nephew, and they were gone. We came in there, and the place reeked; I called a friend of theirs. My niece was in the hospital after my—it doesn't matter, that's where my brother-in-law and sister were. We called a friend who we could stay with. He came, and he didn't smell anything. As it turned out, the gas company had been there, and they'd left the vent gaping open. So we might have keeled over, because we would have been exposed to that overnight; we could have died. I don't know if she had a carbon monoxide detector then, but everybody needs to use those. But anyway. There was in fact, a serious gas leak; whatever they had, they either did not turn the valve all the way, or they hadn't covered it. So it was all coming back into the house. Those are two times that I saved the day. The gas company, when they came, said, "Oh, we should have you come around with us." I said, "Well, if it wouldn't bother me, on some other level physically—if it was just the smelling of it, I would agree to come," kind of as a joke, but unfortunately, I get sick, and make myself sicker. I did things like replace my gas stove with an electric stove, things like that; that hopefully, in the long run will help me. I have an air purifier. All this stuff that I'm trying to keep my—at least home—safe. But I'm still going back to what can we do. I don't know. Have you heard of any?

[01:26:58]

STEVENSON: Those are all great things.

RICE: I talk it up a lot. I mentioned it on social media; I think maybe the people on the social media like Facebook, maybe they just don't really want to help change things. And those groups, because a lot of times they'll say, "Oh, they're out to get us." I don't think anybody's out to get me, you know, fragrant people. I think sometimes people say rude things, or would be inconsiderate, but I don't think anybody's out to get people with chemical sensitivities. Or, "Oh, I said something, so now they wear more (fragrances)." I feel bad for people who are working because they have to deal with stuff that is really hard, so people in the workplace are protected by the American with Disabilities Act (ADA) from what I know. Which I didn't know that much about apparently when I was at work, because I ended up leaving.

STEVENSON: One thing that I wanted to ask you was in regards to your son. So I know that your husband sometimes has these sensitivities. Has your son ever expressed any of these same problems or symptoms?

RICE: No, in fact, I had to get him to stop wearing cologne. No, he hasn't. And my husband probably because he was also exposed to the carbon monoxide. I mean, not probably.

STEVENSON: And does your son have a family?

RICE: No, he's single.

STEVENSON: Have any of your other relatives—I know you said you had a niece and a nephew—have any of your siblings ever mentioned anything about having any of these symptoms?

[01:29:38]

RICE: My sister has had an issue with perfumes and cologne for like twenty-five years. I remember, we were at a movie theater, and we had to move. I think I said I had to do that too. But I remember we had to do it like in the '90s. And I was just talking to somebody who said they'd had a lot more issues after they had kids, which is interesting. So that would have been right. But yeah, she has a problem with perfumes and cologne and a few other things. Nothing I can remember. I know that those are the ones (in which) she has to move, or leave, or say something.

STEVENSON: Has she ever been diagnosed with MCS or anything else? Or this is just something that she comments on occasionally?

RICE: This is just something that she comments on, and that's why she's also well aware. And pretty understanding—they forgot though, they painted and re-carpeted, and it was all good, because it was the better stuff. But I still need to stay away when new stuff is put in. We painted with low VOC (volatile organic compounds), but I still needed to stay away for a couple days. She didn't notice those. So she's pretty specific to fragrances.

I did find a note I had made about—I do these little six-word memoirs. I don't know if you've heard of it. sixwordmemoirs.com. It's basically you do a six-word memoir. There's a reason I'm telling you all this. It's based on the author—I can't think of the name of the author now—Hemingway—but could you write a six-word memoir? Could you write a story in six words? He said he could, and his was, “For sale: baby shoes, never worn”. Okay. So this is the idea of these six-word memoirs that's been copyrighted; there's books and everything. I'm in the book! Anyway, I've got to say something nice about myself. So I've been doing six-word memoirs since 2011. You can write a backstory, and/or include photos. So I've written quite a few. I mean, there's some who've written thousands, but I've written quite a few; I've been on a hiatus for a while, but I've done it. Then I wrote a backstory.

I've written a few about the chemical sensitivities I've had, but one of them was called, “Get the f off my cloud.” Maybe I should send it to you guys. I don't know. It talks about a trifecta. This is a story about it; I could read bits of it that might be a good synopsis of some of the day that I had, how things can be. I'll just read the part of it that is maybe pertinent: “Today's trifecta: Dryer sheets, incense, and scented air. At the coffee shop, I had to move when a guy who reeked of dryer sheets joined his friend at the table next to me. I had to leave a little shop when my eyes started watering after an employee started burning incense near the cash register. And lastly, I had to wait outside, literally, my ophthalmologist's office while my glasses were repaired due to the scented air inside.”

This might relate to talking about what people can do: “I'm thinking of creating a flyer to give to people when this happens rather than just running for the hills, or sharing my thoughts about how carbon monoxide poisoning increased my chemical sensitivity. And it would also explain what MCS is, what triggers reactions and how those reactions manifest, as well as provide suggestions for accommodation as MCS is recognized as a disability—well, in the workplace by the ADA. I spoke to the office manager at the ophthalmologist, and she listened somewhat attentively, but also looked confused and had nothing to say as I registered my complaint. I'm not the only

person in the world who is bothered by fragrance, though you'd think I was from the baffled looks I receive when I mention it. Beware, obtuseness is on the rise. And now I need to find a new eye doctor due to the sickening scentiness of my current one's office and also write a letter to him to let them know why I'm leaving."

An aside, the person I talked to at the desk who wasn't the manager, she said, "Oh you know my mom has that problem too." I mean she just sort of said it offhand, like my mom has problems too. "But you know when I use dryer sheets I use three because I just love them." People are addicted to their fragrances, and I do think that's creating a problem. Anyway, the rest of this blurb is, "The fragrancing of the world via wall-mounted thingies is occurring in hotels, offices, malls, and it's getting out of hand. Soon, I won't be able to go anywhere, and many more will join the ranks of those who struggle with MCS. While people with MCS react more severely to these chemical products and other people, we know that they present a hazard to everyone." So usually when I write I'm a little more fun and quirky, but anyway, so my thing about creating a flyer, that's something you were asking about things people could do. And I did actually start working on that, and I haven't finished it, but it was me, what my triggers are and what my reactions are. And I also have this picture that I use on social media sometimes, and it's a woman lying in a bed and it says, "This is what toxic overload looks like". And then it says, "Go fragrance free. It's good for you. It's good for me." That's another thing that I will put out there on occasion, just like, here's a reminder. That was an aside.

[01:36:22]

STEVENSON: Thanks for sharing that. We appreciate it; that was great writing. It really gave us an insight into on what a day's like.

RICE: I just want to say another aside, but at the ophthalmologist they literally, I think they had stuff pumping in because I remember seeing it, but they also had like plugins, like five or six. Okay, let's say four, in the waiting room area, where people tried on glasses. I mean, it was really overkill. I was stunned. It's funny because I went to a different ophthalmologist. The person who tested my eyes had dryer sheet smell. It was a nightmare. So I came in and had my glasses adjusted, and the woman with perfume—who couldn't wait on me to do my glasses trying on—I came in and she goes, "Are you the person who's sensitive? I can leave." I said "Thank you," but she said, "Well, next time call ahead, and then I won't wear my perfume that day." I thought that was really nice, if I came in and needed my glasses adjusted. And I thought, "Oh, that's really nice that you offer." I mean, that's going above and beyond. So there are people out there who are really concerned and do try to be helpful and make sure they're not toxic around you. I thought that was really a good thing. Like I said, a lot of people aren't really nasty about it.

STEVENSON: I think my last question is just if you have anything else that you want to share. I mean, you've given us such great answers to these questions today, but is there anything else we didn't get to that you want to have on the record?

RICE: Oh my gosh, you might have to call me back.

STEVENSON: We can definitely do that too. But if you want to take a second to go over your notes right now.

[01:38:26]

RICE: I'm looking at my notes. Last fall, I talked about my experiences with MCS at a local storytelling event. I think I wrote this in my notes. The organization is called Ex Fabula, and it's kind of like The Moth, but local. And I talked about the use of scented products and almost belligerently, I told them how I got carbon monoxide poisoning, and how that caused me to become sensitive to chemicals. I compare it to, okay, my body was poisoned once. And now it (my body) says, "A poison is coming in, run." It's sort of almost like a helping mechanism, because it tells me to run because more poisons are bad. I know that that's not probably the physiology of it. But to me, I try to explain it to people that way, because it sort of makes sense.

I went on to say, you can use your dryer sheets, but don't kid yourself that they're fine. And on and on about perfumes and hairspray and how they were endangering not just themselves, but children and their own kids. I did not hold back; I was just very upfront about it. Afterwards, that was nice, because some women in the front were like nodding their heads yes to everything. Some people afterwards came and said, "Oh, I've worked in a nursing home. People were using a spray in their hair, and people were using whatever. And I just had to tell them that they couldn't anymore." I said, "Well, good for you." There's people out there who do appreciate it and who get it. Unfortunately—and this was really frustrating—I'm actually going to advocate again, for this. I talked to the woman who's one of the founders, and she's the main person that runs the organization. I said maybe we can have signage at events like, "We're trying to be fragrance-free, if you can remember next time not to wear perfumes, colognes or any strong lotions." Or we could put something in the newsletter or send an email. She just said, "You know, people don't read." I thought that was a real cop out. I'm going to tell her that—it's just at the end of the season. In fact, the last event is Saturday. And I went in October, told my story. I went back to one, and it was at a bar, and it was really a smaller space than they usually have, so they were really crushed with people. I sat down, and I don't know where the person was, but there were a couple people that—due to how close it was—I was bound to smell them. So I had to leave, and I just haven't even gone back. I used to go to those pretty regularly for the past five years.

So I want to go talk to her and say, "You really need to rethink that comment." What they're really big on is accessibility, and this is something I want to say. My access to things can be so limited, and I am not taken into consideration. People like me are not being taken into consideration at all. Yes, we have wheelchair ramps, yes, we have signing for deaf people, yes, we have accommodations for people who are blind, theaters will have performances for just an autistic audience—so it'll be a little quieter, or whatever they need to help them experience the show better, etc. But there's no accommodation for me. In this group, it really makes me mad because they are very big on that, and have gotten like a wheelchair ramp at one of the events that didn't have one to the stage. They want to make sure that people can get on the stage. And I thought, but you don't care if I have to leave the event or I get sick at the event. It's really the last sort of disability. There's nothing I can do.

I want to say, “So you've accommodated all these people with many kinds of conditions, that might have been prevented from coming, and that is wonderful. But to just ignore this group—you know, it's not like we did something that made us this way. It's too bad if you can't enjoy everything that everyone else can. But we didn't do anything; we didn't ask for this. And now we are being kept out of events and activities because of fragrances and other things.” I don't think people think about that at all. In this case, she certainly could have made a difference, and you don't have to enforce it. It's just creating awareness. They wouldn't have to kick people out but could say, “Maybe you want to think next time about wearing less and leave it at that.” Or maybe change the sign every time to something a little bit different or make it funny. But people are much more afraid of insulting or upsetting people who wear perfume than they are about hindering us from living a full life. It makes me really sad—it's like I'm a non-entity, that I'm a non-person, I don't matter as much.

[01:44:54]

I also asked for the same accommodation—not accommodation, but just creating awareness with some signage at my local grocery co-op. The woman was very off-putting. I called, and then I sent a note, and she said, “Well, we can't take all of our products off the shelf, and we sell products that smell,” and I never asked for that. But she jumped to this thing. All I said was, “Maybe you could have a sign to create awareness.” Because I think that creating awareness can only help. So if I say I have chemical sensitivities, they may have seen a sign somewhere that said, “Please refrain from using fragrances,” or think about it. So it wouldn't be news to everybody or to a lot of people. I'm going to meet with her. I have a letter in for the woman at the storytelling thing; I've a letter in to somebody at the hospital I was at; I'm going to go to Patient Relations there. I've served all these irons in the fire, and it could be a part-time job.

And other things I've mentioned that I should do too—should, but—I want to do the public health stuff, talk to my neighbors. It can get very involved and tiring, and sometimes you don't know what kind of audience you're going to have—if they're going to, as soon as you say something, get defensive or confused. I think that's the hardest part because my friend said, “Just approach your neighbors,” and I said, “I don't know what kind of reaction I'm going to get.” And English isn't their native language. So I thought, “I don't want anything to get lost in the translation.” The woman doesn't speak English very well at all, but the husband does. But I think their daughter speaks it really well—like, can we go through your daughter? Because I don't want to say anything that's offensive.

Some people love their fragrances or are addicted to them. I sometimes will say to people, “It's like when you smell glue, it kind of gives you a high. It's very similar to what fragrances are doing.” Dryer sheets don't smell good. But they have that thing that will get you high. I have a great-nephew who—I tell you this, my great-nephew loves candles. He's on my husband's side; he loves candles. He's eleven now. He loves candles; he loves Irish Spring soap; they get him box after box of that stuff, and I just cringe. When he was visiting my sister-in-law who's his grandma, he was sniffing her laundry detergent. So much so that when my niece (his mom) came home, he had crystals in his nose. They're both intelligent women, you know, and I looked at them. My sister-in-law said, “Well, I couldn't keep it away from him.” She's five-foot-eight. He was three, maybe four. I was like, “You don't have a top shelf? Come on.” And I kind of gave

her a hard time. I said, “Well, that's really dangerous.” I said, “I don't know if you get it, but he's getting high on that. It's like an addiction, almost, and you shouldn't really”—I didn't say shouldn't—but they thought that was fine to just give him every kind of scented thing. When he started sniffing the laundry detergent, you should have gotten a little bit suspicious that maybe this wasn't a good thing. Sometimes you think people know the score, and they're really, really uninformed. Or not thinking, I guess. I mean, really—crystals in his nose?

[01:48:54]

STEVENSON: I think that's all the questions that I have right now. Again, this has been such great information. So is there anything else you want to add before I explain what will happen next? Is there anything else you want to add in this moment?

RICE: I think I talked about my symptoms. And I think I talked about my major triggers.

STEVENSON: Yes, we do have that down. If there is any more that you'd like to add, though—

RICE: Let me just say, I do have a list. I'm just going to read it, because I did have this down because I've used this for other—either for writing something or putting something together, a letter or whatever. This is what I wrote: “Formaldehyde is one of my main triggers.” Formaldehyde is in clothes that come from China. They soak them in that so they don't get bugs. I'm not sure if you guys knew that, but that's why they smell funky. Anyway, that's one of my main triggers. So I can barely walk through department stores, clothing departments, etc. “Glues, adhesives, and solvents, and sealants are all problematic. Dryer sheets send me running inside. Other triggers include scented markers, paints, duplicating odors, colognes, perfumes, nail polish, and nail polish remover, mothballs, fabric softener, dry cleaning chemicals, vinyl, many plastics, natural gas, newsprint. I could go on and on. Most cleaning products that are scented: Nope, nope, nope. I have found a couple products that I use—I found a couple things for my dishwasher, couple things for my laundry, and those are my go-to ones.” So I'll just mention my symptoms again: trouble swallowing, lightheadedness, my ears do occasionally pop, hoarseness, nausea, watery eyes, and headaches, and wooziness. Oh and I think I mentioned this a few times, but air fresheners are really, really bad. And scented, any kind of those—when they try to scent the room or scent a building or anything? So that's all I have for now. Thank you so much for the opportunity.

STEVENSON: Yeah, we really appreciate you taking your time and sharing. I mean, this is such great information. So we really appreciate it.

RICE: Is this gold?

STEVENSON: This is gold, this is one hundred percent gold. So thank you so much.

I'll just explain quickly about what's going to happen next. Hopefully in a month, we'll have this transcribed for you. Then you get the last say—if you want anything sealed or taken off, whatever; if there's something that you mentioned and don't want down in the record—you'll let us know. You can read through the transcript, listen to the audio. So again, hopefully that should

be to you within a month. Afterwards, it will be shared with UCLA's oral history library. That's where we will be keeping it for now. I know that you were super prepared and had such great notes, so if there was something that you're you know, looking back later today, and like, "I wish I had said that or I wish that that was down," we can definitely set up another call or interview or you can email us, email Alexandra. Do you have any questions right now?

[01:52:52]

RICE: No, I don't. And I will look it over. I think I will remember most of what I said, and I think I will look over anything that I—because I have print-outs of stuff that relate to talking to you and then relate to just information that I have for myself on products and stuff. But I feel like there'll be something to be honest. Well, I want to be thorough, and I don't like to be—and at this point, it's too late to do that—but I like to make sure that I'm clear.

STEVENSON: You were definitely clear today, I appreciate that.

RICE: Okay, because sometimes people say, "Well, what did you mean exactly?" And I'm like, "Oh, no, I should be clear, clear." I was really good at writing procedures and being very specific when I was head of the Reference Department, I was always very clear. People couldn't come back and say, "What did you mean by that?" I was like, boom, boom, boom, how do we do this, the procedure's out there, the policies are out there. Not that I'm that organized generally, but I try to be very concise and clear in what I convey to other people when it's stuff like this. I don't want it to be muddled.

STEVENSON: If we have any questions, we will definitely email you to clarify anything, and like Alexandra said, we do what we call a word list and table of contents. Anything in there—if it's an acronym or something that we're not quite sure what was meant—we'll definitely email you back with that. But it's always so hard telling your life story to someone; the timelines are never going to be perfect or never be exact. You did a great job. So we really appreciate that.

RICE: Well, if I think of anything related to your questions, or if I talk to my sister and she says, "Well, you forgot this or that." If anything like that just happens to cross my path that relates to the questions, I'll definitely be in contact. I just want to make sure it really does a good job in informing people. I'm so glad you guys are doing this. This is just awesome. It's just great, I'm telling people about it too and they're like, "Cool."

STEVENSON: If you ever you know anyone else that you come in contact with that has MCS and wants to share their story, we would love to have it.

RICE: You don't by any chance know if you got people from—because that's where I got it from—one of those boards.

STEVENSON: Yeah, we've definitely had a lot of people contact us back from different postings that we've done. It's been very receptive. I think people are so excited that there's finally an outlet for them to share their stories; there currently isn't really.

RICE: Yes, some are really, really sad, and they've lost their jobs—I mean, I did. I lost my job, my livelihood, I never was a librarian again. That's pretty sad. I didn't mention that. That was a real loss to not be able to—by the time I was able to really work again, they're like, your skills are old. Okay. They were only eighteen months old. There's so many losses with this. Maybe that's something I should write in the notes for you guys. Just so many losses. Not just your health, but your sense of security and jobs and all that.

I'll let you go. We had some fun. It was nice meeting you over the phone, and next time I'm in LA, I'll just look you guys up.

STEVENSON: Do you want to speak to Alexandra again? Do you have any more questions for her?

[01:56:54]

RICE: I think we're good. Okay. Nice. It's nice talking to you, Alexandra.

STEVENSON: She says take care. Alrighty. Well, have a great rest of your day, Jacqueline.

RICE: Okay, thanks Grace. Take care. You too. Bye-bye.

[01:57:14] (End of May 16, 2019 interview)

Post-script

Author's Thanks: "I'd like to give a shout out to my friends and family who have supported me since I developed MCS. I know that not everyone has a steadfast support system. So, I'm grateful for their listening ears, their accommodating me time and again without question and their advocating for me. And my youngest niece who's 12 and my nephew who's 9 didn't know me before I developed MCS; they've only known me as someone who gets sick around toxins and are very protective. They alert me when they notice a smell that they think might bother me or tell me I shouldn't go somewhere because they know it was freshly painted, etc. Sadly, my niece is having issues with toxins as well. In any case, their looking out for me means a lot and gives me hope that future generations will be informed about MCS and make healthier choices."