

## Oral History with Maya NoName

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Interview of Maya NoName

SESSION 1 (5/13/2020)

[00:00:09]

ANTOINE: Now that is recording, too. Great. First, I want to ask you if you're comfortable using your own name for the archive. You have the option not to—you have the option to change that at any time—up until we submit it, so you don't have to decide right now. In the next few weeks, it would be good if you would let me know if you didn't want to use your own name.

MAYA: Right. Okay.

ANTOINE: I also wanted, then, to just ask and make sure that I have your consent to conduct this interview.

MAYA: Yes.

ANTOINE: All right, thank you. Today is May 13<sup>th</sup>, 2020. This is an interview with Maya for the Center for the Study of Women's Oral Histories of Environmental Illness interview project. My name is Katja Antoine. I'll start with just some basic demographic-type questions. When and where were you born?

MAYA: I was born in 1957 in—I'm just trying to get a little more comfortable here, where I was (physically) was just not comfortable—in New York City.

ANTOINE: Okay.

MAYA: Let me close the door. I'll be right back. I hope it's okay if I eat a little bit while we talk.

ANTOINE: Oh, yes! Just be comfortable.

MAYA: Okay, thank you.

[00:02:05]

ANTOINE: How do you identify gender-wise?

MAYA: Woman. She.

ANTOINE: All right. How do you identify racially or ethnically?

MAYA: Well, my family is Ashkenazi Jewish on both sides.

ANTOINE: Okay, sounds good. Now, tell me a little bit about your parents and your family background.

MAYA: My mother was born in Israel, while it was still Palestine, back in the 30s. She emigrated after she met my father in Israel, who was a New Yorker, whose parents emigrated from the Ukraine in the 20s. They came back to the United States when she was very young. I think she was eighteen or twenty or something. She's been here ever since. My father passed away in 2015. My mother is still around, still alive.

ANTOINE: Did you live and grow up with your parents or did you grow up with other relatives?

MAYA: I grew up with my mother. When I was three years old, my father left. We lived in New York. I was born there, we lived there until I was two and a half. We moved to Los Angeles and not too long after that, he left and went back to New York. That's when the marriage ended. My stepfather came into the picture when I was six. He married my mother when I was seven.

ANTOINE: How many children were there in the family?

MAYA: Well, to start with, there was me and my sister, who was a toddler when my dad left. Then, after that, my mother and my stepfather had two more children—a girl and a boy—so I have two half-siblings.

[00:04:25]

ANTOINE: It sounds like you're the first in the lineup, so to speak.

MAYA: Yes.

ANTOINE: Could you just describe your siblings a little bit and your relationships with them?

MAYA: I have a sister who's two years younger than I am. Then my next sister is seven years younger, and my brother is about—well, she's about eight years younger, my brother is about nine years younger. My relationship with them—in what way would you like me to describe that?

ANTOINE: If you're close or if, you know, things like that.

MAYA: Well, yes and no. They're all in Los Angeles. We get together for holidays, and things like that. But the family—I guess you could call it a dysfunctional family. It just didn't really gel very well. I was mainly the target of my parents' emotional abuse. I was the main recipient, and the effect that had on the other kids and our relationships was to basically separate us. We've never been that close. Never, really. Maybe my sister, who is the closest in age to me. But she's

never been close to me. I was sort of set up as the scapegoat. It was like nobody wanted to be near me, and they still don't. It's weird, but it's just how it happened.

ANTOINE: How, then, would you describe your parents and your relationship to them? Both how are they as people and how do you relate to them? Obviously, your father is no longer here, but while he was here.

MAYA: Also, my stepdad passed away in 2015. They passed away within a month of each other, which was strange.

ANTOINE: Wow.

MAYA: Well, my mother, now—since my stepdad passed away in 2015, my mother and I have developed more of a relationship than we had before that. But before that, it was not—it was like—I just was not somebody. I just never felt loved or supported, to be honest. It was a long, miserable childhood. It really was. My dad, my biological dad, I remember missing him horribly until my stepfather came along. I realized later that I waited for him for all those years to come back, which he never did. We went to visit him once, when I was eight. I learned much later that that was when my mother had him sign papers, giving up his parental rights, so that my stepfather could adopt us. So, I just saw him once and that was it. Then not until I was sixteen—I saw him years later. My sister and I went to visit family in Israel and he was living, at that point, back in Israel, with a new wife and a son. We visited them, briefly. It was only until I turned thirty-eight—actually, I saw him again when I was twenty-two, briefly. I went to visit him in New York after he'd come back from Israel. Then when my daughter was born, when I was thirty-eight, that's when I got back in touch with him and we stayed in touch until he passed away in 2015. That relationship wasn't very close, either, because he just never—he was in New York, I was in LA. He told me much later that he really regretted that he left the family and he didn't contact my sister and me as much as he wished he had. So, he did tell me. This was practically on his deathbed, he was telling me this. Even though we had a connection, it wasn't super close, which—and he didn't really make that effort because, I think, he had his own issues, his own problems, that he couldn't really overcome. I'm glad that we at least had a few years at the end there.

[00:09:17]

ANTOINE: Right. Why do you think you have gotten somewhat closer to your mother after the passing of your stepfather?

MAYA: I think it's because my stepfather was one of the main engines of the abuse. Not that my mother was incapable of it—she was very capable of it, and she was part of it. They were like a unit. But, once he was gone, whatever his contribution was to all of that was gone. I knew on some level that she loved me. There was, for me, a charade over the decades of showing up for family gatherings and things. Always, in the back of my inner child's mind—Maybe they'll be able to be part of this family in a way that makes me feel good. Honestly, it never really

happened. At least, with my mother, I could develop some kind of a relationship, and that seemed to happen. I think she just didn't have that extra voice always in her ear. She basically abandoned me for him, in a way, as happens, as I've heard other people talk to me about these things when I've shared these things with other people with similar backgrounds. That was my situation, too. Once he was gone, she had more freedom to do what she wanted. She did other things that she wanted to do that she hadn't done until after he died, too.

ANTOINE: How many years, then, did you live in the same household as your stepfather?

[00:11:19]

MAYA: Well, the entire time from the time I was six until I was seventeen and went away to college. Then when I came home at nineteen, I pretty much dropped out of college and lived with them for a couple years until I found my own place. I got a job and was able to move out.

ANTOINE: How would you describe the abuse? You say that he was abusive. What kind would you describe it as?

MAYA: Well, I think that the bulk of it was emotional. It was, in the beginning, I mean—at first, it was like, This was really nice. We had a new Dad, we were like a little family again. Then around ten-ish, nine, ten, is when it really got really a lot worse. There was already a little bit of stuff happening, but he was basically, on the one hand—gosh, how do I—I wasn't expecting to get so deep. Anyway—

ANTOINE: You don't have to answer any questions you're not comfortable with, just so you know. So, you can just say, "Let's skip that one," and that's totally fine.

MAYA: I think what I can say about it is—mostly emotional abuse. There was a certain amount of this bizarre, like, "You're so wonderful," one day, and, "You're so horrible," the next day. My mother, on the other hand, was basically checked out. She didn't want to have anything to do with me. So, the only real parental person I had was my stepdad, who was just this confusing—and, also, when I got to be a young teenager, he made me uncomfortable. There was some sexual abuse involved, but it wasn't of the touching kind. I'm telling you—Boy, I'm getting into it here—it was really unpleasant. I felt unsafe around him. I didn't trust him. He never did anything other than that, which was bad enough. Basically, just, until the day he died, except for maybe—he would be alternately okay, and alternately abusive in this verbal, psychological, I reject you, you're garbage to me, kind of way of behaving.

ANTOINE: How would you, then, describe your family's economic circumstances as you were growing up?

MAYA: Well, they were middle-class. It was a middle-class family. I had nothing to complain about, right? I had all my physical needs met. I had a roof over my head. We went to local

schools that were—we grew up in in Santa Monica, so we went to Santa Monica schools. Yes, middle class. My stepdad was an attorney. My mother was an artist who had her own artist studio in the garage, so she was able to do stuff. She was like a combination stay-at-home mom and artist.

ANTOINE: Okay. How would you describe your childhood home, then—in terms of the house, the physical space, that you lived in?

MAYA: Well, we lived in three places that I remember. I don't remember New York. My first memory was actually on the plane. I was two years old—I remember that. I was on the plane asking my mother, “Are we going to California?” She said, “Yes.” I do remember that—that's crazy. It's like, there was a moment that I just—anyway, after that we lived in Venice in an apartment while my mother was a single mom. Then we moved to a house in Santa Monica, it was a two-bedroom house. Then she met my stepdad while we were living there. When I was—from about the age of five to nine, we lived in this little house, and then we moved to a house in Santa Monica from the age of nine going forward. My mother still lives in that house now.

[00:15:55]

ANTOINE: Okay, all right. Can you recall and describe any smells that were associated with your home as you were growing up?

MAYA: That's a really good question. I don't remember smells. My mother was a good cook, so you could say that. That was one thing she was able to do really well. We did have a swimming pool, like a small-ish swimming pool in the backyard. There was a lot of chlorine in that pool, so I remember that. Other than that, I don't really have any obvious memories.

ANTOINE: Okay. You say she was a good cook. What type of foods did your family eat?

MAYA: Well, that's—she was big on vegetables, fruit. She would go and get these crazy fruits from the store, cherimoyas and really unusual stuff. I guess, growing up in Israel, she also went to a kibbutz and she went to agriculture school, so she had some of that interest in stuff like that. I felt like, for that, we were kind of lucky because she gave us things that were sort of unusual and also healthy. Like, she didn't ever buy Wonder Bread. It was only wheat bread and whole wheat bread, which was fine with me. When I finally ended up tasting Wonder Bread as a kid, it was like, “Yuck.” It was really nice to have—she didn't cook with salt much. We had meat—we were meat eaters. It was a fairly standard diet, I think, but with that twist of—she didn't go for a lot of processed foods. She cooked everything, really.

[00:18:07]

ANTOINE: Did anyone in your family smoke?

MAYA: Yes, my mother did when I was really small, up until I was about five years old. Then she quit. Then she started up again when I was fourteen or fifteen. She smoked for about two or three years. It was awful. Then she quit again, for good.

ANTOINE: Okay, so how did it affect you?

MAYA: It was horrible. I hated it. I was in a bedroom that was right next to her bedroom and she was smoking in her bedroom and the smoke would always get into my room. Complaining about it didn't make any difference. It just made me cough. It was really unpleasant. I hated it.

ANTOINE: Yes. What sort of products do you remember from your home? Things like cleaning chemicals or fragranced products of different kinds?

MAYA: Well, I mean, she used what was available, which was—I remember Tide, for laundry, which was just the standard stuff with the fragrance in it. At that time, I don't think they really had produced dryer sheets back in the sixties and the seventies. I think that you just threw your clothes in the dryer and that was it. We didn't have that, but we did have fragranced everything else—soaps, shampoos, cleaning products, I'm sure there were cleaning products. I don't know what she used. When we got a little older, she hired a cleaner to come in every so often, once every couple of weeks or something. I think it was pretty standard stuff. It was like Windex, floor cleaner, whatever that was. It had the usual fragrances and stuff.

ANTOINE: Did they affect you in any way?

MAYA: Not that I remember. When I was ten years old, for some reason the dentist convinced my parents that they should put in preventative mercury fillings. So, that's what I got, at ten years old. After that, I was having a lot of pain in my joints and my parents, they just ignored it, which was typical of them, anyway. But, I had—looking back on it, I think that that had to do with having mercury fillings. It was right around the same time. I also had a kidney infection around the same time, so I was, like—something was going on with me that wasn't working too well.

[00:21:03]

ANTOINE: This was around what age?

MAYA: Ten.

ANTOINE: Ten. What about perfumes? Did they use perfume or aftershave?

MAYA: I don't think my stepdad used aftershave. I don't remember that. My mother occasionally used perfume when they went out to go to dinner together or something like that. We had, at the time, door-to-door salespeople who came around and—like, Avon or The Fuller

Brush Man. They gave these little tiny samples of perfume to the kids. We would just do all that stuff.

ANTOINE: Did that affect you in any way?

MAYA: It didn't bother me.

ANTOINE: Okay.

MAYA: Yes, not at the time.

ANTOINE: Could you describe your reaction at around the same time that you had the fillings put in? You mentioned joint aches and a kidney infection. Was there more to it? Or could you describe it a little further?

MAYA: Well, I mean, it was a lot of pain in my elbows, my knees. That's when that started. I started to get a lot of pain in my elbows and knees. It just came and went. It was intermittent. At some point, it kind of went away. I don't remember exactly when. After that, every time I got particularly tired, the pains would come back. I would just have that experience again.

[00:22:50]

ANTOINE: Would you say that lasted for a couple of weeks, couple of months, couple of years?

MAYA: Well, I would say that the whole thing—I think I had that long into my adulthood, but it was intermittent. It wasn't constant. There was no swelling. There was no redness or anything like that. It wasn't like it was rheumatoid arthritis or something like that, but there was something going on that I never figured out.

ANTOINE: Did you have any other signs of illness or sensitivities when you were a teenager or young adult?

MAYA: Well, I can go back to nine years old, actually, with that swimming pool. Every summer—we didn't swim in it at all except during the summer. Then it was—I don't know if they even heated it. It was just sort of heated by the sun, so it was warm enough to swim in. I would get really sick. We'd look forward to it every year. We'd spend pretty much almost all day long—at least, we'd spend hours in the pool every single day that we could. The first day, all the time, I don't know how long this lasted, but I think until I stopped swimming in the pool every day as a kid—but every year, the very first day, I'd be so sick that day after we were finished swimming. I was so sick. I was nauseous, I had a headache. I felt horrible. After that, somehow I became used to it. I acclimatized. Or, maybe my liver was put on notice to chlorine, but it was intense. I didn't know any—if I had a normal family, I would have told my parents how I was

feeling, but I didn't even bother to tell them how I was feeling. I just noticed that as a pattern every summer. For the first day or so, I would be really sick.

ANTOINE: So, they never knew? Okay. How would you describe, then, the broader community you grew up in? Neighbors, friends and so on, schools.

MAYA: I went to school, I had—I wasn't somebody who was really all that group-oriented. I tended to have best friends when I was a kid. I really liked my elementary school when I was in kindergarten through fourth grade, and then we moved to just right across the street, practically. In those days, they didn't really care about what kids wanted, so I had to go to a whole other school. We were just a few blocks away; it was in the same school district. So, that was a really unpleasant change for me. The culture of the school was different—it was entirely different. One of the first experiences I had was being teased for my last name, which at that time sounded more Jewish. That stopped. There were a couple of kids who went around telling all the kids who were teasing me to shut up, and they were like the Jewish Defense League at school. It kind of continued on from there—there were a lot of divisions. White kids didn't hang out with Black kids in that school, whereas, in my other school, nobody paid any attention to any of that. It was really unhappy—it was an unhappy transition for me. I did end up having a best friend in fifth grade and a best friend in sixth grade and then I went to middle school. I think, for me, my experience was basically—the good thing about being in this middle class neighborhood was that the arts were valued in the Santa Monica schools. I was chomping at the bit to play an instrument when I was really young, but I finally got a chance to do it when I was nine because that's when they gave lessons for free to kids.

[00:27:36]

ANTOINE: Okay, what did you play?

MAYA: I played clarinet. Then the next year I played oboe, so I started off on clarinet. So, I played oboe.

ANTOINE: Nice. Did you have any illnesses or sensitivities come out during those years in school?

MAYA: I'm trying to think. I don't really remember that in school. I don't remember having any issues in school, any allergies, any sensitivities that I can remember, while I was a kid. I ended up having some stuff when I was a young adult though. That started—that was different. But while I was in school, I was still okay as far as that goes.

ANTOINE: What happened, then, when you got a little bit older?

MAYA: I'm not sure. I had a bout of what probably was mono (mononucleosis) for about four months, when I was in my—I was twenty, something like that, twenty, twenty-one, or maybe

twenty-two—early twenties. It was horrible. It was one of the worst things I've ever experienced because it kind of affected me—it affected my nervous system and nobody ever diagnosed it. It was one of those things where I had these, and I think, late, I think—anyway, it's connected to stuff that happened later, but it was like having an anxiety disorder without having anxiety. I don't even know how to explain it. It was like, everything was like—all my nerves were like “Zzzzzz”—like that. It was terrifying. It was absolutely terrifying. It was accompanied by this fatigue. It started off like that, and I would lie in bed wondering when it would pass and just not knowing what the heck was going on because I wasn't—I didn't feel like I had anxiety.

[00:30:00]

ANTOINE: I understand.

MAYA: I was functioning okay in the world, but—and then, that was followed by four months of exhaustion. When I went to the doctor for that, they checked me out for mono. They said, “Well, you don't have all the symptoms, maybe it's mono.” It passed in four months. If I were an anthropologist looking at—maybe that was the beginning of my shamanic journey. I don't know—I like to look at it in a positive light. But, boy did I have a few other episodes, because it was really—yes, that was strange. I never quite—and it took a while to get my energy back fully. I would go to these homeopathic doctors and these herbal doctors and places where maybe somebody could help me because the regular medical profession wasn't—didn't know what was going on.

ANTOINE: So, it started off with this buzzing feeling of your nerves, so to speak. How long did that last? Did that last for the four months, also?

MAYA: No. That was the first episode. It was like the introduction to the four months of fatigue. Yes, it was—probably, lasted about three weeks. It was a long time. Yes, it was really—

ANTOINE: Then, after four months, when it went away, you say you had recurrences of it? At later dates?

MAYA: Years later, when I was in my late twenties. A few years later—it wasn't that much later, actually. When was this? This was 1988. So, where was I in 1988? How old was I? I was thirty-one. I was in my early thirties, so it was years later. I developed chronic fatigue syndrome. I had that for four years. I'm still not exactly sure what set it off, except that I had a flu to start with. It was classic chronic fatigue syndrome. I had a flu and it wouldn't go away. I couldn't kick it. Then I had that sensation again, that buzzing, nervous, like, my thoughts racing, like, “Zzzzzz.” Terrifying—it was terrifying, and there was a lot of fear associated with it, which was so strange. I thought, “Oh, this feels familiar.” That passed more quickly this time, but the rest of it did not pass. I was—classic fatigue, could hardly get up, was—and that lasted four years.

ANTOINE: Wow, that's a long time.

[00:33:18]

MAYA: Yes, yes, it was.

ANTOINE: What made it go away, do you think?

MAYA: Well, I don't know for sure. I know that I was looking for answers. There really weren't a whole lot of answers. I don't know if I tried, at that time, acupuncture, or—there was this alternative guy who my mother found out about. I'm not sure where she found him. He did this weird magnetic fields thing. I'd lie on the table and he would point this thing, magnetic fields, and, I guess, it stimulated your immune system or something, and he would give me homeopathic remedies. It may have worked. I may have believed in it enough to—or, either way, I don't care. I don't care whether it was real or not. Whatever that means, right?

ANTOINE: If it works, it works.

MAYA: Right. It's real, then—yes, exactly. But I think it helped. I also slowly started to develop—I would go for walks. I had a couple of people that I had met through a group that was for people—basically, it was a twelve-step group for people who had grown up in dysfunctional families. I was already searching out some relief from my childhood experience and how it was still affecting me. We would go on walks and I would go on hikes, slowly. I slowly built up my stamina and I came out of it. I just came out of it. Maybe all of those things put together helped me come out of it.

ANTOINE: Did you have any subsequent episodes of similar nature?

MAYA: No. I never did. Once I came out of it, I was—it seemed like it was gone. But, then, some more years later, unfortunately—you know what, I'm noticing a pattern as we're talking. The beginning of every decade, some horrible thing happens. I should pay attention to this, maybe just noticing it. Actually, I skipped a decade, but in the beginning of my forties, that's when I left my ex, who was my daughter's dad. I met him as I was recovering from chronic fatigue syndrome. I was with him for about nine years and he was very abusive. It was like repeating my family experience. And I left him. I took my daughter with me. She was about five. We moved into an apartment that had a serious mold problem. I got very, very sick. I didn't know why. It felt like—I was exhausted all the time and I had this constant nasal thing. Finally, I just collapsed. I developed—they called it “hyper—” What's it called? Some kind of pneumonitis. I was so sick. I couldn't work, I had to take a break, and for whatever—and, I didn't realize why I couldn't get better. It was like, “Why am I not getting better from this?” It was kind of like chronic fatigue syndrome. I thought, “Maybe that's what this is.” But it didn't feel like the same thing. It felt a little bit different. Well, it turned out the flood we had in the bedroom shortly after I moved in created mold underneath the floorboards because there was a water heater that

had leaked. In fact, it didn't just leak, it flooded into the bedroom. I actually found mushrooms growing up through the carpet in the bedroom closet.

[00:37:32]

ANTOINE: Oh my goodness.

MAYA: Horrible. It took the landlord six months to change the carpet.

ANTOINE: Wow.

MAYA: After the mushrooms had long died, but there we were being exposed to this heavy mold. Then they put a new carpet in, which was full of chemicals. That didn't help. That just crashed me out even further. I was really sick by the time that was over. My ex actually hired—he was a building contractor—and he hired an environmental person to come in and diagnose the problem. They said, “It's mold. That's why you're so sick.” They looked in the closet; they looked around. I got out of there after a year, but it took a year. I was sick for a long time in there.

ANTOINE: What were the first symptoms of that experience?

MAYA: Just being tired all the time, sick all the time, catching every bug that came along. Just not being able to—feeling dragged out. Very tired. I thought, “Well, it's because I'm working two part-time jobs and I have a kid and I'm taking care of her and I'm just super busy.” I was starting to take classes because I wanted to finish my university degree at that point. I thought I was just wiped out because of that. Well, no, that wasn't the reason.

ANTOINE: You said it reminded you a little bit of your chronic fatigue syndrome, but there was some difference. What will you describe the difference as?

[00:39:07]

MAYA: The difference was—first of all, there wasn't that nervy stuff.

ANTOINE: Okay.

MAYA: That was not there at all. It was just this constant feeling of being sick—nasal congestion, upper respiratory, constantly feeling tired all the time and catching bugs and never feeling fully healthy. When I finally collapsed, I was so exhausted. I lost a ton of weight. I couldn't—my sister would come over. Suddenly, my sister paid attention to me and she would come over and do the dishes. It took everything I could to get up and take a shower. My daughter went and lived with her dad again, so there was that separation there, which caused a lot of upset and difficulties for her as well as me. So, that—it was traumatic in many ways. Those were—

those symptoms to start with. Once the pneumonitis went away, I was just tired. I couldn't function. I couldn't do anything. I had to get groceries delivered. I was just totally unable to function. I filed for a social security claim, which never got resolved. It went on for years and they wouldn't give me Social Security Disability.

ANTOINE: Did they say why?

MAYA: What ended up happening—after, I left that apartment and went back to my abusive ex's place and lived with him. So, basically, took care of my daughter for a year until I moved out again. That's another story. What ended up happening is while I did get acupuncture at that time and was doing other alternative sources of medicine again, which, actually, I think, did help me. It helped to get my energy back. That's when I was left with the chemical sensitivities, which just would not go away. Chemical sensitivities, food sensitivities, all of that stuff just kind of followed me. I couldn't handle perfume, I couldn't handle paint, ink. It was bad. It was really bad.

ANTOINE: Do you feel that those other sensitivities came as a result of the original mold exposure?

MAYA: I think, yes—I think the chemical sensitivities came out of the mold exposure. Yes. Now, I do remember being somewhat chemically sensitive during the chronic fatigue syndrome, but it was nothing like what I experienced later after the mold exposure.

[00:42:05]

ANTOINE: You mentioned fragrances as something you were sensitive to.

MAYA: Yes.

ANTOINE: What other things did you have reactions to at that time?

MAYA: Anything that was a petroleum-based product. If it was oil—I mean, motor oil. I could have olive oil. If it was ink, adhesives—

ANTOINE: Ink as in pen or papers?

MAYA: Ballpoint pen, newspaper. I had to go with—I could tolerate those rolling writers, but ballpoint pen ink was just beyond, and to this day I don't use ballpoint pens. Fragrances, of course, fragrances in anything. I had to go strictly fragrance-free everywhere, in every possible way. Nowadays I can tolerate a certain amount of chlorine and alcohol and things like that, just because of what we're living with (2020 COVID-19 pandemic), having to disinfect when we go out and come back, I have to disinfect. I can tolerate a certain amount of that now. I don't know how much, but it's not like it used to be. I was really—I'd get sick from—well, see what else? Fumes, like auto exhaust. I was really in a bubble at the height of the chemical sensitivities. I

was wearing a mask with those two big carbon filter things to go into a store or do anything. At that point, there was a time when I finally didn't care what anybody thought. My embarrassment level was gone. I just did what I had to do. I'd go shopping when nobody was around, at off hours. Everything changed for me. When I went to a store, I'd have to come in and shower and change my clothes, wash my clothes. I had to bring—I had to get a washing machine that was in my house. I lived in a building that had a laundry room. I couldn't use the laundry room because I couldn't tolerate the dryer sheets and their laundry detergents.

ANTOINE: Why did you have to take and wash your clothes when you had been outside?

[00:44:40]

MAYA: Well, only—I mean, if I walked outside, that was fine. But if I went into an enclosed place where other people were, where there were a lot of other people, like the store, or—I stopped being able to go to concerts and go to places where a lot of people congregated because of people's perfumes and stuff—mostly perfume. You never knew who you were going to run into, what they were wearing. Most of the time, I could smell it on me. I could smell my hair, my clothes—they smelled like fragrance. That's the reason why. I was extremely sensitive. On top of that, I got more and more electrically sensitive, too. So, I couldn't even look at a—I couldn't even use a computer. I couldn't use a cell phone. I couldn't put a regular landline phone receiver up to my ear because it would give me a headache. I was just—it was miserable. I could use this regular landline on speaker. So, that's how I talk to people on the phone.

ANTOINE: Okay. You mentioned, just now, that the phone would give you a headache. What were some other specific symptoms of you getting ill as a result of going into stores or fragrance exposures in different ways, fumes and so on?

MAYA: I think that the typical was headache and nausea—were some of the first symptoms. I'd also get joint pains, muscle aches, digestive issues, if I ate something that didn't agree with me, so I was also sensitive to stuff. For years, I didn't eat any wheat, I didn't eat any dairy, I stayed away from sugar. The sugar made me really exhausted. It was—it really sapped me. I was able to eat a little more once I got out of that moldy place and got a little bit better. I was able to expand my diet much more than at first, but I was still really sensitive to certain things like what—so, that was foods. Other symptoms were digestive stuff. It was just all over. Tiredness. Fatigue was the common through line through my symptoms.

ANTOINE: First of all, how long did all of this last—this chemical illness?

MAYA: It lasted from 2001 to 2012. It was a long time—eleven years.

ANTOINE: That's a long time. Within that, when you would have more acute episodes as a result of having been around something, how long would those more acute episodes last, would you say?

MAYA: It depended on what it was that I was exposed to and how long I was exposed to it. I got pretty good at avoiding stuff because I just didn't want to go through a long period of—so, it could be anywhere from a couple of days to a couple of weeks depending on what it was. Sometimes I would just get the headache and the nausea or the headache and fatigue and nausea. It would last for a few days and then it would go away. Other times, I would get that plus the joint pains and the muscle aches, so it would last longer, maybe like a week, maybe even longer, depending on—it was about a week, at the worst. So, it all kind of went away.

[00:48:37]

ANTOINE: When this started, did you seek help from regular doctors or alternative doctors? How was the response from the medical professionals?

MAYA: Well, it was not very good because when I started off seeking help, it was about the mold. It was about the mold exposure. It was about my lungs. It was about—because I was diagnosed with reactive airway disease after having had that pneumonitis because I was suddenly super sensitive to dust and other things that I hadn't been sensitive before to. My descriptions of my symptoms were in keeping with that diagnosis—reactive airway disease. The only thing they could—one of the things that tanked my disability claim was that one of the doctors said, “Oh, yes, she can work. She only has that reactive airway disease.” He didn't listen to a thing about all the other symptoms I was having because they didn't compute. They didn't fit into any of their paradigms. There wasn't a single doctor—until I got into the naturopathic world—who took it seriously. So, it started off with the mold. Then, once I—once the—and so, I stayed with one of the naturopaths that I went to—it was two years after I was out of that apartment and I was still dealing with chemical sensitivities. I found a naturopath who got it. She understood what I meant. I had tried—I mean, believe me, I had tried. Even alternative doctors were not always all that—“What do you mean every—mold's everywhere.” No, I'm sorry.

ANTOINE: Not everyone has mushrooms growing in their closet.

MAYA: Exactly. Exactly. Yes, and I read about that later, that kind of stuff is—I forget the word—but it's heightened. There's an increase in what happens to a person living in that kind of environment, instead of just walking around in the air. Obviously, it's just a greater concentration of mold when you're in that, but—no, it took two years. Then around the same time, I met a doctor who I later was told was taking advantage of people with mold issues. But I found him to be helpful, actually. Because he agreed with me, he understood what was going on. He did what was called an ELISA test for mold antibodies, and I was just through the roof. That was my proof because we didn't get a proper air sampling when I was in the apartment.

ANTOINE: I see.

[00:51:56]

MAYA: But my antibodies were just—the reference range was one through 1500 and I was at 6025, for one. Yes, it was just crazy.

ANTOINE: Wow. So, how was he able to help you?

MAYA: Well, he just confirmed what was going on. He wasn't able to help me—he helped me by getting me those tests. That was the main thing. He actually helped me in a lawsuit I filed against the landlord for neglect because I got so sick from mold. Unfortunately, I went to arbitration. We drew a judge who was sympathetic, and this doctor came and testified on my behalf. I didn't get much money. I got not a whole lot of money, but it did—that really was some substantial help for a couple of years, anyway. I was able to live on that for a couple of years. It wasn't enough to keep me going for a long time.

ANTOINE: How did—well, let me ask you like this, then—did you continue to go to regular medical doctors throughout this time?

MAYA: I think so, but since I didn't really have any obvious normal—“normal”—illnesses, I might have gone maybe once a year for a checkup, kind of thing. That was about it. Yes, I did.

ANTOINE: But not specifically for your chemical illness?

MAYA: No, I would tell them. I'd say, “Yes, I have multiple chemical sensitivity syndrome.” They'd say, “Okay.” They would write it down and that was it. There were probably a few years in there, when I was particularly sensitive, that I didn't go to any doctors. I'm sure that probably did happen, but I don't remember it that well.

ANTOINE: Was there any time during that whole period that you got ill to the point of being bedridden, or close to?

MAYA: Kind of. Post the mold. I was bedridden, essentially, during the worst of the mold exposure. I was. But after that, after I got out of the moldy apartment and started to recover, but was still left with the chemical sensitivities—and they got worse over time, actually. They just got worse until I found a way to heal from it. I can tell you about that at some point. But, yes, kind of. There were times when I was just really tired. I don't know—bedridden? I don't know if I was—I mean, I could get up and walk around. I could go to the bathroom. I could even make some food, but I really couldn't do much of anything. I couldn't promise to be somewhere. I couldn't work because there was no workplace that was safe from being exposed. I couldn't promise to show up at work if I was not feeling well because of an exposure. So, stuff like that.

[00:55:33]

ANTOINE: Yes. Did you also, at this time—I know you mentioned, at some point you had electronic sensitivities. Did that last throughout this period, too?

MAYA: It developed a little bit behind the chemical sensitivity. It started to get worse as time went on. It was a little—there was a bit of a lag time, but I had that for most of the time I was sensitive. Yes, most of the time.

ANTOINE: While you were ill, did you have to advocate for yourself, or did you advocate for yourself? I know you mentioned the doctors didn't really respond. But did you find, at some point, that you had to do that type of self-advocacy?

MAYA: Do you mean within the medical profession or in another—?

ANTOINE: Yes, with doctors, so to speak—or, elsewhere.

MAYA: Yes. I was living with—by some miracle, and this was sort of a saving grace that happened. Again, two years in, it was like, I found the doctor that I would work with for fifteen years. Then I found my partner, a man who I met in an Al-Anon meeting, who also had chemical sensitivities. He just sort of—I don't know how this happened, but he fell for me. We developed a relationship and he took me in, he took my daughter in. We were looking for an apartment, a bigger place because he was in a large single, so it was a pretty crowded place. We ended up finding a place—a one-bedroom place. I discovered that they had electric heating, and it was all on the floor. It was underneath the floors. That's how they heated the apartment. It turned out to be something that I knew I was not going to be able to tolerate because of my electrical sensitivities. I had to advocate for myself. I had to go to a housing rights organization that was funded by the county. They went to bat for me and they helped me get out of the deposit that I had paid these people. Then I also—we eventually moved into a two-bedroom apartment in the same building. We couldn't move out of the building we were in, but we eventually moved upstairs to a two-bedroom apartment. I had to do a lot of advocating for myself, again, with pesticides. They wanted to use a pesticide to get rid of fleas. I had to get a non-toxic flea-killing company, which—and, again, I had to use the same organization. They finally—they got used to me, finally. I was going to fight for myself. It took forever to get them to replace the carpeting in the apartment. That was horrible. That was really bad. But they finally did. They actually pulled up the carpeting and then they refused to put flooring down. We were living on unsealed concrete—

[00:59:07]

ANTOINE: Wow.

MAYA: —for months. I was like, I don't know how to get these people to do what they're supposed to do. Finally, the building inspector came by—buildings inspectors come by once a year, or whatever—and told the owners they have to put some flooring down. It was crazy. They

were going to—they did that for the guy downstairs, but for us, no, they didn't do that. Anyway, so, finally they put some vinyl flooring down with, whatever they used underneath was not harmful—it didn't bother me. Thank God. But I wasn't living here at that point. Oh, boy, you haven't heard the half of it. I mean, it was crazy. My life has been just—my life during that period was so, so much upheaval. After we moved up here and my boyfriend lived here, my daughter was living mostly with my ex. I was living in my mother's backyard in a tent because I couldn't tolerate being inside. I couldn't—and she came and she stayed with me. I insisted. They finally allowed my daughter to come and stay with me—in the tent. It was like, “Hey, we're camping out.” I had her half of the time. Now, meanwhile, my ex was trying to take her away from me, saying I was crazy. He was trying to—he was going to a mediator. Fortunately, he didn't go to court. I was lucky. It was terrible. It was really bad. Meanwhile, my parents were—both my mother and my stepfather were, almost daily, telling me to leave, telling me to get out. There were times when I was homeless. I was sleeping in my car at night. It was horrible. This was even after I met my boyfriend—once I couldn't stay in the apartment because of whatever chemical they used. They used a chemical for the fleas before they used the natural stuff.

ANTOINE: I see.

MAYA: Or maybe it was afterwards. They used the natural stuff and then the natural stuff takes some time to kick in. It takes the life cycle of the fleas. So, you're left with adult fleas for three weeks until the non-toxic stuff kills the eggs and then you never have another flea for your entire life, which is what happened. But, in the meantime, some people did use some chemical stuff.

[01:01:55]

ANTOINE: I see.

MAYA: So, I moved out and I, again, moved to my parents' backyard. Same thing. It was just—this happened periodically, and it was because it was hard to get the landlords to understand. And my boyfriend was not as sensitive as I was. He was actually starting to heal from a lot of this. By the time a few years passed, he was pretty much over his sensitivities. It just happened—

ANTOINE: I see.

MAYA: —for him.

ANTOINE: I just want to check in with you because we're a little past an hour—

MAYA: Yes.

ANTOINE: —to see how you're feeling.

MAYA: Yes, well, I'm ready to stop—for now.

ANTOINE: Yes.

MAYA: I don't know if the chronology made any sense at all because I tend to ramble a bit.

ANTOINE: It does. Yes, I think it has flowed very, very naturally.

MAYA: Okay.

[01:02:51]

ANTOINE: Would you be open to doing a second interview to finish it?

MAYA: Oh, of course.

ANTOINE: We can certainly wait a few days so you have time to relax, or whenever it suits you, or next week or whenever. That will be great. I don't want to—there's quite some—I think we have enough for another one, so to speak. I'm going to stop the recording now but not close—oh, actually, I guess I don't know if I can stop the recording. Do you want us to schedule via email, or do you want to look up at the calendar right now?

MAYA: Yes, let me take a look at the calendar and see what it looks like.

ANTOINE: Oh, I can stop the recording here.

(End of May 13, 2020 Interview)

Interview of Maya NoName  
SESSION 2 (5/28/2020)

[00:00:00]

ANTOINE: —this one and then my backup.

MAYA: Can you hear me okay? There's a lot of background noise.

ANTOINE: Oh, that's fine. It doesn't come through.

MAYA: Okay.

ANTOINE: Well, thank you so much, first of all, for being willing to do a second go of this. Today is, just for the record, May 28, 2020. I'm Katja Antoine interviewing Maya and this is the second interview. I wanted to go backtrack a little bit from where we were last time. There were a couple of questions I wanted to ask you about—both regarding your work. When did you first start working? And what did you do?

[00:00:54]

MAYA: Well, my very first job, I was sixteen and I worked in an ice cream store. I worked in a Baskin Robbins ice cream store.

ANTOINE: That sounds tasty.

MAYA: It was very tasty. It was nice. It was a good little job that I had for the summer.

ANTOINE: What other jobs did you then have following that? What was your trajectory?

MAYA: I think—I didn't work after that until after I dropped out of college in my second year. After that, I went to work at a hospital food service. I was part of the crew that put out meals for the patients in the hospital. I then went and became a cable TV installer for a year or two and then— which, I wish I hadn't done, but whatever. I ended up going to the phone company and working as a cable splicer. Both of those jobs were industrial jobs, climbing telephone poles and—

ANTOINE: Wow. (unclear)

MAYA: —stuff like that. Yes, this is, like, the early eighties. They were trying to encourage women to join these jobs. Not all the guys were thrilled about it, although the people in my class, so to speak, who were hired on with me, were fine. There were some old timers who were fine, too, but—so, I did that for about four and a half years.

ANTOINE: Wow. When you said you wish you hadn't, why is that?

MAYA: I kind of wish I'd stayed with cable TV because I think I could have done more. I could have, I think—it was a smaller organization at that time and I think I could have rose in the ranks a bit and maybe become an engineer or maybe even some kind of executive position or something— decision-making position.

[00:03:03]

ANTOINE: So, you're saying you wish you hadn't left, then?

MAYA: I wish I hadn't left cable TV to go to the phone company to become a cable splicer.

ANTOINE: Okay.

MAYA: But I don't know that either one of them—I was so concerned about what my purpose in life was that maybe I wouldn't have stayed at cable TV either. Who knows?

ANTOINE: After doing cable splicing, then what did you do?

MAYA: Let's see, what did I do after cable splicing? Let's see. I have to think about this for a second. In the '90s—well, shortly after that, I tried to find work in various places and I found a little job with some people who made video discs. I think those things are no longer current technology—

ANTOINE: Right.

MAYA: —but, at the time I was doing—sorry about that, I just spilled something. Okay.

ANTOINE: You mean, like floppy disks?

MAYA: No, video discs. They were, like, solid—they were like the old LPs. They looked like the old LPs.

ANTOINE: Oh, okay.

[00:04:36]

MAYA: They were that size, if I remember correctly, but they were video. You could play them on a player and get a video, and you could connect it to your computer. This is late '80s, early '90s, in that region of time. I was tasked to transfer—I can't remember what I was doing. I think I was transcribing something off of a video disc and putting it on to computer database. It was

like a survey of the Earth's biology by kingdom, family, genus, etc. It was accompanied by some beautiful photographs. I really enjoyed doing that because I could just look at the pictures and write down on a computer program what they were. That was my job for about a year. It was run by some really dysfunctional people so I kind of left after a while and then went canvassing for Greenpeace for a summer, thinking, "Okay, I don't know what to do next, I'll try to figure it out." Then I got sick. I got chronic fatigue syndrome. I started being unable to do anything. I was so exhausted. Actually, I think that the video disc thing came—I can't remember the chronology anymore, to be honest, whether it came before or after I had chronic fatigue syndrome, but I think it came before. Yes, it did, it came before. That lasted for four years.

ANTOINE: The video gig came before chronic fatigue?

MAYA: I couldn't work. I ended up getting Social Security Disability. That was the way I was able to support myself. So, from '88 to '92, I had that condition. Halfway through that period, I was starting to get better.

ANTOINE: Did you make any connections between the chronic fatigue and any of your work?

MAYA: Yes, I think that my exposure, possibly, to a lot of electromagnetic fields when I was working for the phone company. I spent a year working in one of these huge vaults—cable vaults—where some of the crews were, and I was on one of them. Hang on just a second. So, some of the crews were changing over to new cable, this huge office—telephone office—exchange area. We were underneath the building and in the vault, surrounded by cables, working cables. My guess is—I don't know for sure—but it could have been that all of that exposure to electromagnetic fields had an effect on me. I was exhausted after that. I was tired. I was—I still kept trying to pursue work. By the time I got to the Greenpeace job, I was feeling the effects of it. I think I started to feel some of that anxiety I described to you before, preceding the exhaustion I had for a few months. Well, I felt it again. I thought, "Uh oh, what's going on here?" It might not have anything to do with my work. I don't know. But I felt like, "Oh no, this is a repeat because it's the same feeling," something was kicking up. I didn't know what it was. I got sick with a bug and I couldn't get over it. It was classic chronic fatigue syndrome with all the symptoms. I had to go to two doctors to get properly diagnosed. Once I got diagnosed, it was clear what it was. Then I was on my own because they didn't have a cure for it. They didn't have any treatment for it.

[00:09:33]

ANTOINE: So, how did you get through it?

MAYA: Well, I think I might have mentioned that, when we discussed in general—that was when my mother sent me to this strange fellow who was doing these magnetic fields and homeopathic remedies and homeopathic interferon and things like that. I went and I did that, and it probably helped, who knows?

ANTOINE: Whether the work was the cause or not, we should (unclear) I understand you're not sure about. It did impact your ability to work, significantly, since you had to go on disability.

MAYA: Yes, I had to go on disability. The illness significantly impacted my ability to work. Yes, absolutely.

ANTOINE: Yes. How, then—so, I'm going to hop forwards a little bit again. Because you had talked about the experience with mono that you had had previously, you talked about the chronic fatigue, you talked about the mold exposure, and the sensitivities that followed after that to fragrances and petroleum and ink and adhesives. You mentioned that, all in all, you suffered through chemical illness at some time from 2001 to 2012. So, as part of the (unclear), I wanted to ask you, if you have gone to any muscle testing, where you tested positive through muscle testing, for chemicals?

MAYA: Kind of, yes, when—two years after I really got sick from the mold exposure, I finally found a doctor who I felt like I could work with. She did a version of muscle testing. It was not exactly the muscle test—well, yes, she actually did. She did the thing where, she tried to do that, and—she did, and it really was helpful to me because I felt that it was accurate. It seemed to show what I was dealing with. And it worked because what she was doing for me was helping me with supplements and homeopathic remedies and things like that. She was very sensitive to what my sensitivities were, which were legion—including food. I'm sorry, I'm still dealing with this water. She was able to really help me. Whatever she did, it really helped my energy level. It really improved it, so I was feeling more normal again. The peculiar part of it was that these chemical sensitivities were as strong as ever, if not stronger—they just never went away. So, just boosting my energy level and giving me supplements and things that helped that just didn't fix the chemical sensitivities for me.

[00:13:04]

ANTOINE: How, then, did you get through the chemical sensitivity because I know that based on your description you're on the other end of it, so to speak.

MAYA: Based on my description, what?

ANTOINE: You have come out of it.

MAYA: Yes. Here's what I—my sister got online and found a couple of people who were doing this, something—it was based on neuroplasticity. That was the theory behind it. I ended up going to a guy named Ashok Gupta, who's based in London. He's a medical doctor and he had chronic fatigue syndrome. He said that chronic fatigue syndrome and multiple chemical sensitivity syndrome were connected and the problem was neurological. He based his program—he had chronic fatigue syndrome himself. He cured himself of it by using this—when he researched it,

himself, he was looking at things like people who had had strokes and had to retrain their brains to use a different part of their brain for the same functions that they've lost. They were able to recover some functioning by doing certain movements, and so on. That's part of the research out there. He used some of that to apply to his getting better from chronic fatigue syndrome. His theory was that your brain on a macro level wasn't damaged, but it was rewired in a way that made you hypersensitive to chemicals that most people don't have that kind of reaction to. Most people don't have a reaction to perfume, for example. He developed a protocol, which he then taught people and had seminars. It was—for a couple hundred bucks, I got a CD set and started listening. I started doing what he said to do, which was a combination of visualization, actual physical movement, and I think some of it was based on neurolinguistic programming. He put all these things together. It was really interesting. He put all this stuff together. There was some meditation practice. I just took to it and it worked for me. Just a few days later, I could feel, “Oh my god, this is really”—his theory was correct because, whatever was going on, it was working. It was like the key, and it was amazing. Anyone who has these kinds of illnesses, I recommend some sort of—I recommend that to people, really. And I thought (crosstalk)—

ANTOINE: —(crosstalk) Does he still do this program?

MAYA: I'm sorry?

ANTOINE: Does he still do this program?

[00:16:27]

MAYA: Yes, he does. There's a Facebook group that I'm part of. I got well in 2012, so they're still doing it because it works. People do it. People use it for chronic fatigue syndrome, chemical sensitivity syndrome, fibromyalgia—anything that has a neurological aspect to it, and all these really difficult to treat diseases and people don't really know what the problem is, kind of thing—or, traditional Western doctors don't know. He was wanting to do a research study and I don't know if he ever did, but it works. He calls it—it's [guptaprogramme.com](http://guptaprogramme.com) and—program spelled the British way, with an extra M-E. Yes. He came to LA a few years ago for a workshop, and I went to it. I was one of two people in the room who got almost one hundred percent better and everybody else was kind of in the process. But I did this for—I did the routine. You start off doing a daily routine, every single day, and then once you get it under your belt, you can do sort of a shortcut to it. I was doing the shortcut every time I felt an exposure. Every time I felt symptoms coming on, I would do this practice. It would kind of calm the—and I felt it. It was like this calming effect, like, I could feel—it was almost physical, I could feel it. It was obviously doing what he said it would—the amygdala was cranked up too high, and there's also other organs that—later on, he talked about as the years went on. When I started it, he was only talking about the amygdala. He also talked about the insula later, and some other brain organs, but it didn't matter to me. What he did was give me a process that worked.

ANTOINE: Yes.

MAYA: It's amazing.

ANTOINE: It sounds amazing.

MAYA: The thing that was interesting about it—and I actually told my naturopath, who I really loved, who had helped me all those years, but couldn't get me cured from MCS—I told her about this and she said that she recommended it to people in her practice. The thing about it is you really had to be disciplined. You had to just do it. I was so done with being—with having this. I didn't want to live the rest of my life like that. So, I was on it, on it, on it. After about—I think, overall, it took about a year and a half. They say after six months to a year, you should be, like—if you're really doing it and it's working for you, you should be done with it. Not really done with it, but you should be feeling a lot better. For me, a lot of it was pushing the envelope. I had to make myself uncomfortable. I had to try things that I knew were going to make me sick or had made me sick in the past. For example—and it helped everything. It helped my chemical sensitivities; it helped my electromagnetic field sensitivities. It got rid of some of those food sensitivities that I was dealing with. I couldn't eat—there's a whole list of things I couldn't eat, that bothered my stomach. It was gone. It was really amazing. My naturopath, before all this happened, she said, “This is a central nervous system problem. That's what this is.” She focused in on that, but she couldn't really do anything about it. This guy figured it out, apparently—for me, at least. And it worked.

[00:20:45]

ANTOINE: How is the—Do you still do the routine in the same format to maintain, or not anymore?

MAYA: No, in fact, the one thing I really think I really should do is, meditation. I think that would help me. I think it would help every—it helps a lot of people, right? If they have any kind of anxiety or whatever. But, no, I don't do any of it anymore. I just don't. It kind of—I'm assuming my brain got properly rewired. Now, I'm like—don't have to. If ever there were a time when I would start to feel symptoms again—and this happened in the beginning. If I felt symptoms again, I would do it. I would do the process, I would do—and it would help. But, like I said, it took a year and a half because, finally—the last thing I did that I realized I was okay, was put a regular telephone receiver to my head. I used to get all these—feeling tingling sensations and headaches and things. I do have some leftover issues that I still pay attention to. I don't know how people put cell phones up to their ears. I can't do it. I get a headache. It hurts. I just can't. So, I don't bother. I don't use any fragrances at home. I use no chemicals at home. I keep my home fragrance-free and chemical-free. That's just bottom line, for me. Other than that, I can go out into the world and I don't have any problems at all.

ANTOINE: The things that used to trigger you in the environment outside don't anymore.

MAYA: Correct.

ANTOINE: That's amazing.

[00:22:27]

MAYA: Yes.

ANTOINE: Congratulations.

MAYA: Thank you.

ANTOINE: Wow.

MAYA: Yes. I mean, I have to—let me qualify that a little bit. If somebody is wearing a very strong fragrance or cologne or something—oh, it bothers me. I would still—if I, somehow, were a teacher in a classroom or something, I would ask people not to come with perfume or cologne. I would just make that a rule for my classroom just because, it's—I just don't like it. Maybe it reminds me of my past. Maybe I'm still a little bit sensitive on some level. Things like going to class, it's—when I went to school, I had no problems at all. I had no problems being in classes except when somebody was wearing something really strong, I'd go sit in another chair in a lecture hall or something. Or, if somebody—I can't stand smoking, but I'm—a lot of people can't stand smoking. Going to concerts, no problem. Going to a restaurant, if somebody would sit down and—in places where, in the past, I would have to get up and leave—now, I just sit there and I usually don't notice it, after a while. The impression of somebody's perfume just goes away.

ANTOINE: That's impressive.

MAYA: Yes. It was a (unclear) long time coming.

ANTOINE: I will go back to when you were in the (unclear) at the beginning of the chemical illnesses and sensitivities. How was the discovery process, if we can call it that? How did that come about? I'm assuming it didn't flick from one day to the next, all of a sudden, all of these things were triggers. How did that process of discovery—realizing that this and this and this was affecting you in a harmful way.

MAYA: Yes. I think it started when I was in the moldy apartment, and I was so sick. I could hardly move. I was just lying on my sofa for three hours a day. I was just really off. It was awful. I just got worse and worse. I could eat fewer and fewer things. I was losing weight like crazy. I was so sick. I was exhausted. I was living in an apartment that had new carpet, so I was so sick. I think the first thing I realized was that I couldn't sleep in my bedroom. I had to go in the living

room and sleep on the sofa because the smell of the carpet was bothering me. That was in the moldy apartment.

[00:25:53]

ANTOINE: Okay. I should also ask, does anyone in your family have a history of illnesses or sensitivities of the kinds that you have experienced?

MAYA: Well, my mother—no, not of the kinds I've experienced. Nobody in my family has had chronic fatigue syndrome or multiple chemical sensitivity syndrome. My mother tends to be a little sensitive to medications, and so do I. But, other than that, I was the only one that I know of.

ANTOINE: How would you describe the effect of this on your social life and the activities you could be a part of or do?

MAYA: Well, it completely limited it. I was lucky that—at that time, I was going to Al-Anon meetings. It was getting worse and worse and eventually I had to stop going to meetings. But, before I did, I met my partner, who also had environmental illness. He heard me share at a meeting and he came up to me afterwards and handed me his business card and on the back it said, EI six years. I was like, “Oh, okay, that's really interesting.” Through that friendship, he ended up suggesting that I could come and stay with him anytime I needed to because I was having serious housing problems. I was living in a tent in my mother's backyard. I think I might have told you some of that. He was the only one—I forget, I lost my train of thought, what question was I answering? I'm sorry.

ANTOINE: No, no worries. Well, how it affected your social life and the activities that you were able to be part of.

MAYA: It limited, eventually—it just kept getting worse and worse because I didn't have the understanding of what was causing it, so I didn't know how to reverse the process. The process just kept going on and on—this heightened sensitivity kept getting more and more heightened. For example, you asked me a minute ago how I started noticing my sensitivities. I didn't have electromagnetic sensitivities to start with, but I noticed that I developed—I'd spent a lot of time on the computer, at one point. I had a laptop that I spent a lot of time on. Suddenly, I started to feel like it was just bothering me. I was getting headaches. I was getting—so, my sensitivities were triggered. Then, it just—I could—that was it for me for electrical sensitivities for a long time. So, yes, it did isolate me. I figured out how to use a regular landline phone on a speaker. I didn't go to Al-Anon meetings anymore. Fortunately, I still had my partner, who was with me through the whole thing. I was taking care of my daughter, so I could still do that. I could still take care of my daughter, so I was, like—my energy was okay. I was kind of feeling normal but, with this overlay of sensitivity. When I drove, I would go out with my big mask on—my N95 mask with the carbon filters. I'd be driving around, I didn't care, at that point. I would go to the store with my mask on. I would look crazy. Will and I went to the opera and I wore my mask the

whole time. Nobody cared. I mean, they just looked at me, they kind of, like—I wasn't doing anything. I wasn't hurting anybody. I just looked weird in my opera clothes and a mask. I got used to doing that. I just got used to building this sort of bubble, carrying my bubble around with me. I didn't have a lot of friends. I didn't do a whole lot of stuff. I couldn't play music anymore with people. There was a whole, long period in there that I was limited.

[00:30:25]

ANTOINE: Did you have friends that were able and willing to accommodate you?

MAYA: By that time, I had become so isolated that—the friends that I had, when I was first getting sick, were just this little, small group of people, which, actually, I don't regret not being around them anymore. At the time, I was working at a school, so I was developing relationships with people there. Once I got sick, that ended. There was just no carryover from where I was working. There was no carryover from these people that I had been hanging around with that were part of a twelve-step sort of thing. It was just like a small group of friends that—we had a meeting of our own. Looking back on it, there wasn't a whole lot of support there. One guy in the group kept in touch with me, and I kept in touch with him for years later, but everybody else just wasn't really around.

ANTOINE: When you say you stopped going to the Al-Anon group, was that also related to your sensitivities?

MAYA: Yes.

ANTOINE: What was it about the group there, then, that that was triggering?

[00:31:49]

MAYA: Well, it was the fragrance problem. It was the fragrance problem. Later on, groups started to—at first, nobody thought of it as an issue, like people didn't think about smoking as an issue years ago. Currently, there are some fragrance-free meetings, as far as I know. That didn't happen soon enough for me. By the time I was too sensitive, I just couldn't go back to meetings.

ANTOINE: You mentioned working at the school. I know we left off with you canvassing for Greenpeace.

MAYA: Yes.

ANTOINE: So, from there, did you go to some other school, or was there something in between?

MAYA: Well, from there, I was sick for four years with chronic fatigue syndrome. Then, as I was coming out of it, I started volunteering at a little environmental organization—a nonprofit. I started working for them, just general stuff. It was a part time job and I started to do some interesting stuff there, but they could only offer me a part-time job. I heard through them of another part-time job that paid better and was closer to me, so I decided to do that. I worked for them for three years. Eventually it became a full-time job. I was the office manager at this organization. They were a dance and movement studio and they had classes. I was the office person. I was their only office person.

(Redacted section 00:33:43- 00:34:27)

Then I got pregnant with my daughter. I had met my daughter's dad in 1990, right in the middle of my recovery from chronic fatigue syndrome. In '95, I got pregnant with my daughter, and she was born in November. I just took the time off. They were talking about the possibility of bringing me on again and being able to bring my daughter, but they changed their mind on that. I ended up staying home. My ex was a carpenter—a building contractor. He was making enough to support us without me having to go to work. It turned out to be the best possible solution for us because, any earnings I could get would just go to childcare, which was ridiculous. I might as well stay home with my own child, which is what I prefer to do anyway. That's what happened. For four and a half years, I was taking care of Shira. I started working part time at the school that I was telling you about, as a teaching assistant. My goal, at that point, was to go back to school, finish my BA, get a teaching credential and become a teacher. I was working at an elementary school as a teacher's assistant. I was there for about a year, little less than a year, and that's—and I had moved out by then. I had moved out to that moldy apartment, and I got really sick there. I had to quit my job. Everything fell apart. Shira had to go back and live with her dad, which was very unfortunate. There's a lot of stress around all of that, too. I couldn't take care of her and he was not sympathetic to my situation. I ended up—I can't remember all the story I told you, but as far as work goes, I didn't work for years after that. I couldn't.

[00:36:43]

ANTOINE: How were you able to support yourself?

MAYA: Well, I was with my ex for a year. Then I left and went to my mother's, but they had a mold problem in their house, and they use fragrances and stuff, and they weren't very sympathetic. I ended up sleeping in a tent for a couple of years, for—how long was that? It was probably a year. I finally got my daughter to come stay with me half time. After that, I met my partner, Will, who took me in, took Shira in. She was still going back and forth between me and her dad, unfortunately. At least we had a roof over our head. He basically supported us. He supported us for years, until I finally got well enough to get a job in early 2013—because, by the end of 2012, I was looking for work. I was well enough.

ANTOINE: In 2013, what did you start working with?

MAYA: Well, I was looking for any possible thing that could make some money. I always thought, Well, I still have this ambition of being a teacher, so I'll work with kids. I went out and I found a family to work for, as a nanny to elementary school boys. That was actually a good job. They were fair people and the boys were—we loved each other. It was a nice job. Then, I—it was a part-time job and I needed a full-time job. By that time, my partner, Will, had lost his job because he was developing early onset dementia, which was really hard. He was not able to work. He was getting social security at that point. I really needed a full-time job. I applied for—and got—a job as an administrative assistant at a school in the Santa Monica-Malibu Unified School District. But, as my luck would have it—I live under a cursed star, Katja. As luck would have it, the school they assigned me to, the principal was brand new. It was her first year as a principal. I was new, too. My job was very pivotal in the school. It was nice that I got that job and I was able to do the job fine, but she hated me. She hated me. She was turning to another person in the office, who was more experienced. She'd been in the job. She just hated me. She didn't trust me. She thought I was too new. She didn't give me a chance. I had to go to the union and get the shop steward in the school to talk to her, but nothing could move—because everybody liked me except her and this other person, who were sort of teamed up. I did a fine job. It was crazy. I did a fine job, but I was probationary. I could tell, after every evaluation—this woman is just not seeing what I'm doing. She's not giving me any credit for anything I'm doing. It's bad. HR (human resources) understood. HR actually allowed me to leave in good standing and said—and, I made a point of asking, “Can I please put on future job applications that I didn't resign to avoid being fired, please?” They said, “Yes, you're fine.” Because, they kind of—they even knew. They even knew. Anyway, it was horrible. It was really sad because I was thinking maybe this could be my career because I enjoyed it. I like being with the kids. I like being with the teachers and I liked doing it. But that was not meant to be. I was there for six months.

Then, I went back to—I kind of substituted for the family, again, that I nannied before with because their nanny was out with a broken leg. I was doing that for a couple months after. Then, I found a job with the City of Santa Monica, at the airport, working as an office person doing a particular project that they hired me for. It was a temporary job. I applied for the full-time position there, but I didn't get it, so I was there for a year and a half. I just worked all the hours that they allotted for the temp job, and that was it. I had to leave. After that, I found a little teeny job doing—I was at the visitor center at the Marina Del Rey. That was also a temp job. It was like two months, three months. After that, it was just like, this is crazy. I have to just go to school and get my bachelor's degree. Nobody is ever going to hire me for anything worthwhile if I don't finish my education, and I don't even want to be without an education, anyway. That's not who I am, right? That was 2016. A couple months later, I was in the (school) counselor's office and started in January of 2017.

[00:42:30]

ANTOINE: All right.

MAYA: I haven't worked since—because of being in school and then getting cancer and having cancer treatments.

ANTOINE: How are you able to meet your financial obligations and things like that with that, then?

MAYA: Well, my biological dad passed away in 2015. He left me and my sister and my half-brother an inheritance. I was just living on that, and basically that's what I've been living on. It's running out. I only have a few months left. That's it. I don't know how I'm going to survive, honestly, Katja. I don't know. I've been looking online for remote work, like everybody, like all the forty million people who are now out of work. If you hear of anything, let me know.

ANTOINE: Yes, definitely.

[00:42:27]

MAYA: Yes, I mean, really, I would love to—I've been looking now. It's worrisome, to say the least.

ANTOINE: Do you have contact with friends who are also sensitive to chemicals? Like has your experience brought you (unclear) friendships or community with people who have the same experiences as you?

MAYA: That's a really good question because, at one point, it kind of did. There were a couple of friends who also had a mold issue. They weren't as chemically sensitive as I was, but they had one thing after another—a couple of twins, two women. But they moved all over the country. They ended up in Arizona for a while, so we just sort of—they were trying to find a healthy place, clean air and everything. I don't know where they are now. I really don't. I think they're Facebook friends. I could probably find out, but as far as a community now, the closest thing I can say to that would be this Facebook group that I found through the Gupta people who had done the Gupta program. I'm considered a Gupta graduate. I recently discovered this—some of them started that group, kind of like a subgroup, just to talk to others who also pretty much got well from the process. I haven't been participating in it lately—because I only recently started with them—because of all the stuff I'm going through now. Fortunately, I was able to join the music ensemble this quarter as a community member. I've got a project I'm doing and stuff like that. I'm actually somewhat busy, which is crazy given the circumstances.

ANTOINE: That's funny because I was going to ask, also, if you were part of an online community, and you just addressed that already.

MAYA: Yes. Another one I'm a part of—a sort of political blog site where there's a community. There are a lot of subgroups there. People cook, there's cooking groups, there are book review

groups, there's all kinds of stuff. I got involved with one of those groups, more politically oriented. We're now having Zoom meetings every other week, which is fun. That's fun.

ANTOINE: From what you've told me, the times when you have been ill, the different times when you've had—whether it was chronic fatigue, or mold, or the mono—these have been times when you actually couldn't work. So, the issue of getting accommodations at work—has that been an issue for you? Or was it just not—because you couldn't go there anyway, so accommodations wouldn't have helped? Or has anything come up as something that you have requested, or that has been provided for you in some way?

[00:47:20]

MAYA: Yes, that's a really good question. At first, before I really got well enough to go back to work, I just couldn't work. I was too sensitive. I couldn't do anything that they would have wanted me to do. I couldn't use a computer, couldn't use a phone, et cetera. Once I got back to work, and I suspect—although I don't know for sure—that this is why they didn't hire me on permanently at my last job that lasted a year and a half. They liked me fine, so I couldn't figure out why they didn't just hire me on permanently. I think it might have to do with the fact that we had some rainstorms and there were some leaks in the building and my station, where I was sitting, the carpet got saturated. It got moldy and it was really bad. I said, I'm having—because of the mold situation, I'd been diagnosed with reactive airway disease, which is a form of asthma. So, I was feeling it. I couldn't sit there. I could smell it. I couldn't sit there. I said, “Look, this is a health hazard. This is not okay for me.” Well, some other guy sat there and said it was okay. He didn't have a problem. Basically, they sent me to a doctor through the city and the doctor said, “Yes, change the carpet.” So, they did. They changed the carpet. They even had somebody come by and test it. They found bacteria, but not mold, so maybe they were just checking some part of the carpet that only had bacteria, not mold—who cares, the bacteria was bad enough. I'll take bacteria, that's fine. But when I talked to my supervisor, and he said he really liked it—I was a little worried about whether I would react to the new carpet. I seemed to be okay. There was enough airflow in there that I didn't have a problem with the new carpet, which was good, because it meant that I was still holding my recovery. My recovery was still holding.

ANTOINE: Yes.

MAYA: He said to me—there was some moment where I said, The doctors—I forget what the—at some point during the conversation, he said, “How did you convince the doctor?” Exactly. Like, what? How did I convince—? “How did you do that?” It's like, “I have asthma. I already told you I have asthma. What do you mean, how did I convince the doctor?” So, they didn't believe—it's like, geez Louise. I actually did you guys a favor. I took a health hazard out of your office environment and you're acting like I'm crazy. I was the nicest person. I'm not this big meanie. I don't force people to do my bidding. I'm very nice. I did a great job for them. I did the project they wanted me to do, really well. Nobody had any complaints. But the fact that this issue, I believe, was probably the reason why I didn't get the full-time job. Yes. Because some

people just didn't get it. They just didn't. I'll bet you, you have a lot of interviewees who have had similar problems.

[00:51:08]

ANTOINE: Did it come up at any other job? In terms of you requesting some kind of accommodation or asking for it?

MAYA: No, but what I think happened—this is really something I'm glad you're asking about because I don't know if you have any suggestions for me, either. One of the things that happened during this whole time was, especially when I was really sick, I was pursuing another Social Security Disability claim. I could not get it. I took it all the way up to—if you can believe this—the Ninth Circuit Court of Appeals. When we went through the Social Security process, first of all—I only found this out later—I didn't have a very good representative. We ended up drawing a judge who was a hanging judge—the kind of judge who just doesn't grant disability to people. That didn't help either. When I got another attorney, he took it as far as he could and they still denied me. He said, “You know what, you could appeal this if you want to, but I'm not going to do it.” I had to find another attorney. I didn't find an attorney, I found these representatives who turned out to be—I guess they did the best they could, but then they blamed me for the failure, as if I didn't tell them everything, which wasn't true. I don't even remember the details anymore. It was just so weird. I remember talking it over with somebody later and they said, “You were not at fault. You were not at fault.” How could I be at fault? I'm the client. I don't know anything. I don't know the law. I told them everything I knew to tell them. I told them everything I knew to tell the previous attorney. I don't know who was talking to whom and what they were saying. I was cooperating with these people. I had an attorney who was verbally abusive to me. I found another attorney who was brand new to the case. I thought I was trying to help myself. Apparently, there was some miscommunication or something. Anyway, that's all in the past. The real problem for me, now, is that my private medical information, including the filings for District Court and the Court of Appeals, are now public. They're accessible to the public.

ANTOINE: Wow.

MAYA: So, anybody who I want to go work for, can Google my name and can probably bring some of this stuff up and listen to it and hear the representative arguing in front of the Ninth Circuit. The Ninth Circuit Judge is asking, “Well, what is this? Is this physical or is it mental?: And, my representative saying, “Well, we're not sure. We don't know.” Somebody can listen to this and say, “Well, she's nuts. She's a nutcase. We're not going to hire her.” I'm afraid, given everything—my age, everything now—I'm worried that I will never get another job because of this, ever. That's my big fear. Nobody is ever going hire me for anything.

ANTOINE: Yes, that's very disturbing.

[00:54:46]

MAYA: Yes.

ANTOINE: I don't know off the top of my head, but it's certainly something that I can ask some of the other interviewers who have talked to a lot of people, in terms of sealing the information.

MAYA: Yes. I did what I could. I tried to talk to the representatives. They ignored me. They didn't care about me. The guy yelled at me on the phone. That was the last thing I heard from him. He would not file a request with the court to seal my case, which—he told me my case would be sealed. It was not sealed. They were the ones that fell down on the job. They didn't follow up with that. I did it myself. I managed to get them to transfer the case back to me as a pro se. I was my own advocate at that point. I wrote a letter and I never got a response. If they sealed it, I don't know. I later went to Google search engines—a couple of different search engines—and made a request to get rid of these links, but it's like sorting through strands of hay—that needle in the haystack thing. It's like sorting through every link you can get—you just have to go link by link by link. It would end up in these private companies that put together case files for lawyers that you pay, it's like a service. There would be links from those people. There would be links from every—it's like, how do you get rid of this? The search engines would do it because they understood that it was a medical issue that was being exposed, but I don't know if it's even possible to get rid of it. I mean, I'd be willing to keep trying, if it's worth trying.

ANTOINE: Wow. Yes, it sounds very distressing, I have to say.

MAYA: Yes.

ANTOINE: I will ask if people know of anything, that are involved with the project.

MAYA: Yes.

ANTOINE: I will ask and find out. Wow. So, have you, during all of this—meaning your experiences of the illness, have you received support in the form of mental health counseling, formally or informally, to cope with the stresses of having the illness itself?

MAYA: Yes. I think two things really helped me, substantially. I did seek some therapy—I did get some therapy. It was nice to talk to a couple of different people over time. I think the thing that gave me the foundation, really, that helped me through the whole thing was Al-Anon—the process of doing the step work and the whole process of doing Al-Anon. I got enough of it before I had to stop going to meetings, and I had sponsors who gave me a good foundation. I was able to sponsor people, even, through this, believe it or not. I could get on the phone with people. I sponsored somebody who, my—Will was in AA (Alcoholics Anonymous) first so he was in AA for a number of years. He went to Al-Anon after that, which is how I met him. He had a sponsee who needed—who was sober and wanted to have an Al-Anon sponsor, so I became her Al-Anon sponsor. That relationship was magical. It wasn't—I don't know if you've been familiar

with this yourself, but people say that sponsoring people helps the sponsor as much as it helps the sponsee. So, it was a phenomenal relationship. She moved to Connecticut a few years ago. We're still in contact. It's a very close, wonderful relationship. I think that the process that I learned there was profound, and it really helped me cope. I could turn to, however I envisioned a higher power. There was always some kind of support. Then, of course, Will. I think Will saved my life, to be honest. I really do. He picked me up out of my mother's backyard and gave me a place to stay and fell in love with me. We created a little household together with my daughter and—he was amazing. He really was. I think that was key—those two things.

[01:00:09]

ANTOINE: Can you talk a little bit more about your friend—the process that she shared with you or that you learned from interacting with her?

MAYA: Oh, well—you mean, the person I sponsored?

ANTOINE: Yes.

MAYA: Okay. Yes, well, I could also tell you what I learned from my actual sponsor, when I first got into the program. That was like—she and all the people in the program gave me a perspective that I just didn't have. As I got more and more familiar with the process of working the steps, what does it mean to apply that to your life and to experience some of the profound—I mean, it was a spiritual experience for me. It really was. It was profound for me. I kind of learned—and it was very therapeutic. What I learned was that all of my childhood conditioning that was so painful, was conditioning. It wasn't me, it was what I learned—and if I learned it, I could unlearn it. This was a process, in a way, to unlearn so much of that conditioning, so many of those beliefs I had about myself. The fact that my sponsor could say—I don't know if you know the wording, the language of the steps. They—at one point, there's a phrase that talks about your character defects. That's an old-fashioned, 1930s, 1940s kind of way of putting it. People would say, “Well, these are my injuries, this is what I do because I'm hurt. We don't want these things, they're not working for us anymore.” People brought maybe a little slightly more enlightened verbiage to it. Nonetheless, the interpretation was the same. These are the things I'm doing that are not helpful to me. I learned what that was from my sponsor in Al-Anon—it was low self-esteem. That was a character defect. Giving your power away to other people, letting them control you, instead of using your own heart and mind to make decisions about your life. That doesn't mean you don't listen to other people, but really you're the ultimate decider—you and your higher power, together, are the ultimate deciders of your life. It empowered me tremendously because—and people-pleasing. I was a people pleaser. I was trying to make people like me all the time because I felt I was so unlikable from having grown up in the way I had. It was profoundly spiritual and therapeutic, that whole process. When I became a sponsor—interestingly enough, my sponsor, I think I was with her for maybe a year and a half. I would have stayed with her, but she started getting really weird. That's what you get when you get peer counselors and they don't have training or supervisors. People get weird sometimes. So, I had to

let her go. I was kind of sad about it, actually. But I took so much from her before that happened. I just—she really was fantastic, honestly. She really was.

[01:04:00]

I took that and I also took what I saw Will doing, as a sponsor. He was extremely compassionate. He was patient, he was kind, he was beautiful with people. That was what I wanted. I wanted somebody to be that way for me. If nobody was going to be that way for me, I could be that way for somebody else. That's how I was with my sponsees. This particular sponsee and I, through the process that we went through, she had two relapses. She called me up one day, from a parking lot of her job, and said, "Maya, I'm smoking crack in the parking lot." I said, "Do you know a rehab? Do you have a phone number for a rehab?" She said, "Yes, I do, actually." I said, "Well, call them and tell them you're coming. Do you have anyone who could drive you?" "Yes, I do. I could call some people in AA. They'll drive me." And she just did it. She did—because we had developed this connection already. It was miraculous to me when I think back on all of that. She went through that twice. I think part of it was because I learned how to be compassionate toward myself while going through the Al-Anon work I was doing. I saw Will and how he helped people. I was able to bring that to the people that I worked with. I don't know if that's what you're asking, but, really, it was a very important relationship and it still is for me.

ANTOINE: Yes, I mean, I was looking to hear about what helped you cope on an emotional and psychological level with everything that was going on.

MAYA: Yes, exactly. I mean, that whole process. Al-Anon was a godsend in every way. It really was, in spite of weird people. There's—I ran into many, many people who were not lovely, but the whole process for me was beautiful. It really was. A lot of people there were wonderful. I still do a Zoom Al-Anon meeting once a week. That's my other group. Yes, that's true—that's my other group, my other circle.

[01:06:30]

ANTOINE: We're a little past the hour already. Time flies.

MAYA: Okay, I hope I didn't talk too much.

ANTOINE: Well, no, it's okay. I don't want to wear you out. I want to be mindful of your time. So, it depends on how you are feeling.

MAYA: I'm fine. Today I'm having—the last week or so, after I crashed that first time when I couldn't—I've really, really improved. I've really been very careful about my self-care and I'm fine.

ANTOINE: Good to hear. Well, how about a last question to end it with, so to speak?

MAYA: Okay.

ANTOINE: This should be a broader one. If you look back at all the experiences you've had with chemical, environment, illnesses, sensitivities, all of it, how would you say that your views toward illness and sensitivity has changed as a result of having gone through all of this yourself?

MAYA: Well, I'm clearly compassionate toward people who have this issue. I understand exactly what they're going through. I'm, of course, grateful I'm not going through anything like it anymore. Thank God. I just have some leftovers, is how I look at it. But—is that what you're asking? Like, how do I—?

ANTOINE: Yes, how has it changed your view, both on illness and, I guess, maybe on life, I could say?

[01:08:02]

MAYA: Yes, yes. Oh, yes. It's upped my compassion. I was already, I think, a fairly compassionate person. But, certainly going through something like this just gives you an inside view of how tough it is to deal with it, and people often do not understand. People didn't understand what I was going through. I, probably, before I went through it, might not understand—"Well, huh, you look okay." You hear people say, "Well, you look fine." Well, you're not fine. How do—you know, my family didn't understand me. One of my sisters started to understand me, toward the end of it. That's how I found out about the thing that actually helped me because she started to understand. But, yes, I mean, it's really hard to truly understand unless you go through something like this, because it's just so out of most people's experience. It's a very weird kind of illness as far as most people are concerned. They just don't understand—basically, they don't understand. So, I do. I do. It also, probably, has given me an overall feeling of compassion for anyone going through any kind of unusual physical illness, mental illness, even people who are just suffering and struggling, just in a general sense. You can't really judge people. You can't say they should be doing this, they should be doing—no. It even gave me understanding that not one thing works for everybody. People have different kinds of bodies and experiences. I learned through Al-Anon and my own experiences that people have a right to make their own decisions about their lives, whatever that is. If they choose a way that isn't my way, that's okay. That's their way. I respect that. There's a lot of an opening up of my heart and my compassion and my understanding, and my willingness to be open. I think I was already, but it really expanded it quite a bit.

[01:10:43]

ANTOINE: Thank you. You say your sister actually turned you on to what ended up helping. Did she recommend the Gupta program?

MAYA: Well, she said, “Hey, I found something that looks like people are getting some good results from.” She actually found two different people who were doing something similar. I chose the Gupta because he was not—this other woman was just charging a lot of money and it felt a little bit like she was taking advantage of people. So, I chose this other guy who just seemed more on the up and up and I think he really was. I think I chose the right one.

ANTOINE: Clearly. All right, do you have anything that you would like to add that I should have asked and didn't think to ask? You're like, “Why isn't she asking about this?” Anything that strikes you.

MAYA: I can't really think of it. I think your questions were really thorough. And, really, thank you for seeing if there's anything that can be done about this stuff online and how people handle that because ever since I found out about this, I've wondered if maybe some of the reasons why I couldn't get a full time job, like I was saying, maybe it wasn't just because people in the office were skeptical. Maybe somebody googled me and said, “Well, we're not going to hire her on full time.” I don't really know. Nobody could tell me that because that's illegal. You're not supposed to do that. But, yes, so I appreciate that.

[01:12:31]

ANTOINE: I'll see if there's any advice that the other team members have.

MAYA: Yes. And, honestly, if you guys want to hire me on as a team member because I know that I'm going to have my bachelor's degree and I have some research experience—

ANTOINE: I will definitely make sure to mention that, should it happen. Unfortunately, with everything that's going on, UCLA has put a hiring freeze on everything, which is discouraging.

MAYA: Yes.

ANTOINE: But I will certainly keep my ears open for you.

MAYA: Okay.

ANTOINE: I am going to turn off the recording.

MAYA: Okay.

(End of May 28, 2020 interview)

