

Oral History with Rowena Ilagan

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Interview of Rowena Ilagan

SESSION 1 (6/14/2019)

BLACK: So, this is Blair Black interviewing Rowena Ilagan. Did I pronounce your last name right?

ILAGAN: Ilagan.

BLACK: Ilagan. For the Chemical Entanglements Oral History project on June 10th at 11:34 (a.m.). Okay. So, can you tell me a little bit about your background information in regards to where you were born and something about your family background, please?

[00:01:05]

ILAGAN: Sure. I was born in the Philippines but I was raised here in Los Angeles. And I went to school at Occidental College, studied Chem (chemistry). And I had worked in the science field for several years before I came down with MCS. Is there any other specific things I should add to that, or—?

BLACK: So, basically, just about your parents, as well, and your family background.

ILAGAN: Oh, my parents and my family background? My parents are still both living. They are in their seventies. What else about the background? My mom is a retired teacher and cafeteria school supervisor and my dad's a retired engineer. Not really sure what else to add to that background there.

BLACK: Do you have any siblings?

ILAGAN: And I have one older brother. He's older by two years and he has a family of his own with three small children.

BLACK: Okay. What did your parents do for their work?

ILAGAN: My mom taught sixth grade back in the Philippines. And when we all moved here in '85, she was working in the cafeteria at several elementary schools as the supervisor, and then my dad worked as an electrical engineer.

BLACK: Okay. So, could you tell me a little bit about your childhood home?

ILAGAN: That's very broad. Something specific about my childhood home or—?

BLACK: Like any smells that you associate with your home?

[00:03:19]

ILAGAN: Well, there's the childhood that I spent—the first eight years—in the Philippines and then the rest of my childhood here in LA. Smells—I don't really have anything that stands out in that sense, sensory-wise. I didn't develop the MCS until my thirties, after I got chronic fatigue syndrome.

BLACK: Oh, I see, okay. So, no one in your immediate family was smoking around you as a child or anything?

ILAGAN: No, no, nothing like that.

BLACK: Okay. And so, nothing in your community in the Philippines and then here in LA had any distinct chemical pollution or chemical smells that you remember?

ILAGAN: No, not childhood. I didn't have any sensitivities, or allergies, or any kind of illness when I was younger. It's only in my late thirties, and early forties, is when the sensitivity kicked in.

BLACK: I see, okay. So, then, what was school like for you, let's say, in college?

[00:04:39]

ILAGAN: College...I was studying chemistry. Yeah, when it comes to health issues, I didn't really have any in college. I was still going to school and it was just rigorous because it was a science major. But health-wise, I was fine.

BLACK: When did you first start working?

ILAGAN: I graduated in '99. So, I started working as a high school chemistry teacher after around 2000 or fall 1999 or around 2000. And then I had some jobs that related to science, like working in the lab and working at UCLA. And then I had an environmental job, which I think triggered a lot of the health issues that I have now.

BLACK: Can we talk a little bit about that environmental testing lab job that you had, please?

ILAGAN: Yes. I worked for the City of LA (Los Angeles) and I was in industrial hygiene. So, I would go to different facilities that the City of LA has now that test the workers' exposure to particulates, different chemicals, like lead—what else?—mold, asbestos. I worked in that field for about seven years. And I medically retired in 2014 when I got the chronic fatigue syndrome. And maybe a year after that I started becoming chemically sensitive.

BLACK: Okay. Can you describe some of the symptoms you were feeling before you were diagnosed?

ILAGAN: In regards to the MCS or the chronic fatigue?

BLACK: The chronic fatigue.

ILAGAN: I would get sick maybe once a month. And they couldn't tell—at least, my primary doctor didn't know what was going on—why I was getting sick so often. And then I started getting symptoms of mono (mononucleosis), which lasted about a year. So, I had chronic mono. And I would get other infections. I'd get fatigue, migraines, vertigo—let's see—oh, muscle spasms, muscle aches. So, that was the onset of chronic fatigue, and they think it's chronic fatigue and fibromyalgia. Those are the main symptoms I got with the chronic fatigue syndrome.

[00:07:23]

BLACK: How did that end up affecting your working at this job?

ILAGAN: I couldn't return to work, and I was on disability. And then, once the time for disability ran out, I applied for medical retirement. So, I didn't go back to industrial hygiene.

BLACK: And how did your employers react to the symptoms that you were having and your diagnosis for chronic fatigue?

ILAGAN: I wasn't really in communication with them as much when I was very sick like that. They just knew that I was on disability. And my employer or my boss knew that I was sick, but they weren't really aware of what my symptoms were. So we had talked about maybe having accommodations, but with a field like that there's not really a place for me to go. Because I could only be in the lab or out in the field and either way, I'd still be exposed to chemicals. So it just was impossible.

BLACK: At this point, how did this affect your social life and your friends?

ILAGAN: I was pretty much homebound, so it was very limited. And most of the communication I would do was just online when I can, when I felt well enough. And the time— Yeah, so about three years, I was homebound and I would just go to medical appointments and that was pretty much my life for three years.

BLACK: I see in the pre-interview (questionnaire) that you managed to have micro-jobs working for nonprofits. What was that like?

ILAGAN: Right. When I was kind of getting a little bit better, maybe in the third or fourth year, I applied to be a volunteer with Solve ME/CFS Initiative. And they focus on research on chronic fatigue syndrome. I helped out with the editing for patient stories. I did that remotely. And then that was pro bono. And then the director offered me a contract job where I would do the social media promotion of their activities. And I did all that remotely and just about maybe fifteen, twenty hours a week so I could work on it when I was feeling well enough.

[00:10:10]

BLACK: Were you able to maintain any of your hobbies while you were doing your micro jobs and then being homebound?

ILAGAN: Just writing, because writing didn't tax me too much and I could always— Because the chronic fatigue is kind of unpredictable. Some days I'll feel well, like I can do some, be outside a little more. Other days I have to be in bed most of the day. So, it was mostly writing is what I was able to keep up during that time when I was mostly homebound.

BLACK: So, now I would like to shift our topic to when you found you were diagnosed with MCS. How did you discover the causes of your illness and your sensitivities?

ILAGAN: I noticed there was a shift when I was sleeping outside. There was someone from this passage, this passerby smoking, and I caught a whiff of that. And it took me over an hour to feel better because I couldn't breathe and—I don't know how else to describe it—I just couldn't breathe and I didn't feel normal. And I've never had that kind of sensitivity before. So I thought, “Okay, this is kind of unusual for me to just have this reaction to secondhand smoke because I never was that sensitive before that.” But I think that's when I noticed, “Okay, there's a shift here,” that I might have MCS (multiple chemical sensitivity). And then my integrative MD confirmed that after I described what happened.

What else? If I would wash my clothes, and I went a few places, and I would wash my clothes and I would get rashes and allergic reactions from the cross-contamination of the detergent. So that's another thing that I noticed that wasn't like before. And even foods that I would eat that weren't organic, I would get a full-on allergic reaction, like a full-on body rash. Like, “Okay, that's new.” So that's when I knew that something had shifted.

BLACK: Okay. Was there ever an initial period of time where you just became very, very sick from your sensitivity?

[00:13:07]

ILAGAN: The allergies, yeah. I had to go to the ER a couple times because of the allergic reactions that I didn't know what I was— that I had become so sensitive. So just a lot of trips to the ER.

BLACK: Did you ever bring up your chemical sensitivities to your doctors? How did they respond to it?

ILAGAN: I brought it up with my integrative MD, and he had me fill out this questionnaire to rate my degree of sensitivity. And that was pretty much it. There wasn't really any treatment other than avoidance. And then I was also seeing a Chinese medicine practitioner and she said that over time, I would become less sensitive. So, there wasn't any specific protocol or anything that I could follow. I just had to avoid being exposed to those other chemicals that I wasn't that sensitive to before.

BLACK: The doctors, how did they respond to you bringing up your chemical sensitivities? Were they receptive to you talking about it? Or were they dismissive?

ILAGAN: My doctors?

BLACK: Yes.

ILAGAN: They were receptive, because they had seen it before. I think if I were to go to other mainstream doctors, they wouldn't really accept it. But my integrative MD, he knows about chronic fatigue, and chemical sensitivity can come along with it. So, he wasn't surprised that I developed it. And same goes for my Chinese medicine practitioner. They had seen it before so they weren't dismissive about it. That's why I went to them, because I've gone through the hoops already. Yeah, I went to a lot of different doctors. I had to find people who were familiar with chronic fatigue and with MCS, so I stuck with those two.

BLACK: Okay, I see. So, in a sense, you had to advocate for yourself as a patient trying to shop for doctors who knew what you were going through?

[00:15:29]

ILAGAN: Right, right. The first two years, it was a lot of shuffling between doctors trying to find someone who could help me and diagnose me properly and give me treatment. And in the beginning, they didn't really know what I was going through.

BLACK: Have you also muscle-tested positive for chemicals or—? How was the testing process for seeing if you were sensitive to chemicals and environmental illnesses?

ILAGAN: For some things, like when I had a reaction to something I ate, and my Chinese medicine practitioner said, “Oh, it must be the chemical or the pesticide in that food that you eat.” So, in that sense, she muscle-tested me, but the other things like the cigarette smoke like when I would take a Lyft or an Uber and I’d get sick from the air fresheners. I couldn’t really muscle-test that. I just documented it in a chemical sensitivity scale, this document that my doctor gave me.

BLACK: How did you first attempt to treat your illness and your sensitivities?

ILAGAN: I think as I got better with chronic fatigue syndrome, or become stronger, then my chemical sensitivity also got better. I became almost back to normal—almost, but the sensitivity is still there. The advice I got from both practitioners was first to heal my gut, because it’s linked to my immune system. So I had to change my diet. And also the environment that I lived in; I had to be mindful of moisture issues and mold and dust. And I tried living near the ocean. That helps with my recovery because the air is cleaner near the beach. So, I’ve had to do a lot of changes, like with diet and moving, and a lot of different supplements that I’ve had to take. I did a DNA test that showed that I wasn’t detoxing well so I had to take a drug for that. And I continued with the herbs when I would come down with something. It’s all those things.

BLACK: Can you describe any family history of illnesses or sensitivities that you know of?

ILAGAN: With my dad, I know he’s had seasonal allergies. His sinuses would act up when it’s cold out and there’s a change in weather. My mom, not so much. I think more on my father’s side. But I don’t think any family members experienced any chemical sensitivity. And I think when I did the DNA test, it showed that my illness was triggered by an environmental— It’s all environmental, it’s not genetic.

[00:18:47]

BLACK: How has your chemical sensitivities affected your relationship with your family?

ILAGAN: With social gatherings, I’ve had to modify things a bit. I mean, I’ve gotten stronger now that I’m not as sensitive as I was, but I would limit the time I spent at social gatherings because it would affect me when people have strong perfumes or detergent. I could sense it, and it would make me sick. Yeah, and I just prefer to be outside. I don’t—I’m more careful about spaces that I would go in, when I don’t know if it’s safe for me to go in. Things like that I’d have to just be mindful of. It’s kind of restrictive.

BLACK: How has your sensitivities affected your ability to just work or go outside or pursue your hobbies?

ILAGAN: With work, like I said, there was no way I could continue in that job and be exposed to all those different hazards. I had to stop that line of work. And then I started doing some teaching, a little bit of teaching and activities for seniors. And that helps in that I don't— I know for sure that I'm not going to be— It's not as dangerous to my health, chemically, with teaching. I've had to shift gears with my job all together because of the chemical sensitivity. And then sometimes at work, it's not such a big issue but when they clean and when they use chemicals there, and I've had to let them know I'm really sensitive and I can't be around (those chemicals). I don't go into that much detail about it, because it is a disability, but I just do the best I can to avoid situations where I'll get sick.

BLACK: How have others helped or accommodated your illness in, say, for instance, work or even when you were going to family gatherings or gatherings with friends?

ILAGAN: It's been mixed because it's not easily understood. So most of the time, I just prefer to not attend something than attend something and try to explain it and not get the understanding. I just cherry pick what I can, what activities and social events I can go to.

BLACK: Have you met other people who also have chemical sensitivities?

ILAGAN: Yes, and they also have a history of chronic fatigue syndrome or fibromyalgia.

BLACK: And then how were you able to meet these people?

ILAGAN: I went to a support group for people with chronic fatigue syndrome.

[00:22:14]

BLACK: Okay. How exactly did your relationships with people around you change after discovering with your illness and your chemical sensitivities were? And this could be friends or romantic relationships or maybe your immediate community where you live in.

ILAGAN: Yeah, that's kind of a fine line. When I was extremely sensitive, I guess I didn't interact as much, because I was just too sick. But as I got a little bit better, I guess I used that opportunity to inform others of what it's like. And some are receptive, and can empathize with it, and some don't really understand it. So, it's kind of been a mixed bag. And so, I've been able to gain strength from people who do understand where I've been through it. And the others— I mean, I don't impose it on them. Because it's hard to understand unless you've experienced it yourself. And I've had people tell me how angry they get because they are trying to make family and friends understand, but it's hard to understand what it's like. So I share it if I can feel like that they're receptive, but if not, then I don't. It's just been a mixed experience.

BLACK: Is this something that you bond over with people who also react to chemical exposure or who have chemical sensitivities?

ILAGAN: Yes, it's something that we talk about a lot with the friends that I made at the support group. That's what we talked about what we struggle with health-wise.

BLACK: How do you feel after finding this community, actually—people who relate with you?

[00:24:16]

ILAGAN: You know, it's good, because then you don't feel like you're going through it by yourself. Especially in the early stages, when you're still sifting through all the medical treatments and the doctors, you don't know what's going on, so you're scared. But once you find people who've been through it, then that becomes your social support. So yeah, it helps to have people who have gone through it and to have people who can treat you and know what they're doing, as opposed to when I was at the early, early stage when I had no answers.

BLACK: Have you been able to meet up with anyone from your group? Is this an online—I'm sorry, you'll have to remind me again—is this an online group, or is this an in-person group?

ILAGAN: At first, it was online, when I was mostly homebound. And then as I started going to those support groups, there's a chronic fatigue support group that meets once a month. So I would get to meet them and we would spend time together that way. And then as I got stronger, I could go to the YMCA and do a little exercise too. So, I got to make friends and meet some people who have chemical sensitivity, as well.

BLACK: I want to shift our attention to activism and advocacy. Can you describe any accommodations for your sensitivities which you've benefited from?

ILAGAN: With the new job that I have, it's mostly teaching and running activities. There's nothing really that I could request as a special accommodation, because it's a non-issue there. So, I think it's not really relevant to work, but I just had to— When I would rent different places to stay in, then they would try to accommodate me, like with the carpeting, and I would choose places that are away from construction sites, because I would react to that, too. And I guess it's mostly to do with housing not so much at work, because it's a non-issue at work.

BLACK: Can you describe when you first learned about activism for your illness and how it impacted you?

ILAGAN: How did it impact me? It was a good outlet, because it gave me something to focus on. And being able to help other people who are going through something similar. And I started doing that with the nonprofit. It felt good to be able to help in that regard and to spread the message about it to other people. So it was a good outlet for me.

BLACK: Okay, and you said you started your activism through volunteering for the not-for-profit that you volunteer for?

ILAGAN: Yeah, that's where it started.

[00:28:11]

BLACK: Do you consider yourself a community organizer at this point or—?

ILAGAN: I would think so. Even if it was online. I mean, I considered myself— I could probably do more. It's just, looking back on my journey after I got ill, I was very different from when I was first diagnosed, and then midway, and then this partial recovery. So it's like an up and down journey. Some days I'm a bit more vocal about it. Other days, I don't want to bother anyone with these issues. So it kind of fluctuates, my advocacy fluctuates.

BLACK: How did you first learn about your not-for-profit that you volunteer at?

ILAGAN: How did I hear about Solve (ME/CFS Initiative)? I might have done some online searching at first, and then I contacted them and I went to the office in person. And that's how I got to know them. And they were going to set up an office for me there, too. But at the time, I was still getting symptoms every other day so it was impossible, but that's how. I think I just did an online search and talked to Emily, who is the advocacy coordinator, and got started that way.

BLACK: Okay. Have you ever protested for any reason related to your chemical sensitivity?

ILAGAN: Maybe. Let's see, after my work with Solve ME/CFS Initiative, I joined the MCS—There's a group online for MCS. And I haven't been as active in that as I have been with CFS (chronic fatigue syndrome). So even though there are many issues there and I put my two cents in— But I haven't done any major organizing for the MCS group.

[00:30:36]

BLACK: I know you talked about a little bit of the barriers that you face in your own activism. Have you perhaps heard from any of your colleagues what kind of protest activism is most effective and/or ineffective and why?

ILAGAN: I haven't gotten to that level with my other contacts who have MCS. I mean, I've had some friends and they went. The main issue that they push is CFS. They want to advocate for CFS first, and then the chemical sensitivity is kind of like a second issue. So that's been how I've done my advocacy work, too. It's mostly CFS and then secondary is the chemical sensitivity.

BLACK: Did someone mentor you into activism or advocacy or is continuing to do so?

ILAGAN: A little bit, like Emily, who's the director at Solve ME/CFS. She would go to Washington DC and do some advocacy work there and I would follow up with her. And then I have another friend, Autumn, I think she attended the March for Millions Missing and that's for CFS. I would get updates from them about the kind of work that they're doing and I would post about it, too, on my own site, or when I was still actively helping Solve ME/CFS I would post it on all of our connections.

BLACK: Are you proud of any particular achievements that you've made with the not-for-profit that you worked for?

ILAGAN: I think I helped some patients there that were getting frustrated about running into dead ends with their doctors. I would share what helped me and I think they were grateful for that. Also, while I was helping Solve, I created this—what do you call it?—a guide to help caregivers for ME/CFS patients and I think that was well-received. And what else? I compiled a list of practitioners that you could go to in California that knows about CFS and MCS. I think that those things that I contributed while I was working with Solve, I think that's helped a lot of patients.

BLACK: Okay, so we will now shift our attention to the next topic, so basically just your present daily life—

ILAGAN: —Okay.

BLACK: —So how does your chemical sensitivity impact your daily life?

ILAGAN: My daily life, it's mostly avoiding things that I know will be triggers for me. Let's see, I used to take, when I couldn't drive and I was still very sick with the fatigue and the fibromyalgia pain, certain cars—when they have air fresheners and certain things—that would make me very sick. So that is something that—I don't know how I managed to do that. But I just I think I was able to work around it because I applied for free transportation to my medical appointments, and they weren't using any air freshener. So that became a non-issue. Now it's not so much of an issue because I can drive myself, I'm strong enough to do it. What else with my daily life? Could that include also my interactions with people if I know they're heavy chemical users?

[00:35:22]

BLACK: Yes, absolutely, I would love to hear that.

ILAGAN: Yeah, I was seeing someone, and he liked to use a lot of— They're essential oils, but I still have sensitivities to that as well. And he was not a heavy smoker, but he was an occasional smoker. So, I had to end that connection, because I couldn't be around him and not get sick. Things like that I've had to also modify.

BLACK: Can you describe some of the products that you keep in your home that are impacted by your chemical sensitivity?

ILAGAN: That affect me negatively, or—?

BLACK: Negatively, yes.

ILAGAN: I can't even name a brand, but most detergents I have a reaction to if they're sensitive so I use a baby-safe detergent with no fragrance. And then I don't use any perfumes or anything scented on me, and as much as possible I use baby soap. What else? What is the most immediate products that I can think of? It's just mostly— Oh, and when I go shopping for clothes, I can't— I mean, my tolerance to synthetics has gotten better, but I used to get a really bad reaction with polyester so I would wear organic cotton clothing and have to wash that several times, because even if it's organic would still be chemically treated, so it needs to be washed several times. So my clothing choices had to be different. Let's see, what else? There's a temporary place that I stayed at, as a rental, but I would get a reaction from leather, because that's chemically treated as well. So I stopped sitting and sleeping on the leather couch. Things like that I would discover. I think that's about it that I can think of right now.

BLACK: Do accommodations for your chemical sensitivities pose a financial burden to you?

ILAGAN: It does, because— I think ever since I got sick, I mean I've had so many expenses that go along with the treatment and then trying to find things that work, and then the herbs themselves, the Chinese herbs are expensive. They're—I forget how much. Every time I go for a visit, a visit will cost me \$200 out of pocket because it's the consultation plus the herbs. And it's just extra steps when you're trying to find things that work well with your body. You can't just grab some things and think that's going to be okay. You have to check and make sure it's going to be tolerated. Yeah, there's extra things you got to do, and there's money involved also.

[00:39:04]

BLACK: Have you ever received support in the form of mental health counseling, formally or informally, to cope with your illnesses during chemical sensitivity?

ILAGAN: Informal counseling, I've had. Actually, let's see, towards maybe the third or fourth year of having CFS and the chemical sensitivity, I joined this—it's like a counseling program where you get trained to be—I don't know what's the correct name for it—it's just like you're more of a coach, not really a licensed counselor but you help. Again, it's a nonprofit. I got some training and at the same time, I got to know some other licensed counselors there and I would talk to them about my health issues. So I got

some counseling there. And then even spiritualists would help me on the struggles that I had with getting ill. I've done that through the four years that I've had this.

BLACK: I know you said that you also have chronic fatigue. How do you feel that affects your chemical sensitivity?

ILAGAN: If I'm getting a flare-up with chronic fatigue, usually my sensitivities are also heightened. They kind of go together. I noticed it. I think that's their link. It's like when I'm getting a flare, I'm getting more fatigued or pain at the end of the day, and I'm more sensitive to scents and smells in general.

BLACK: How has your treatment of your chemical sensitivity and your chronic fatigue changed over the years?

[00:41:13]

ILAGAN: I'm not taking as much medication as I did when I started. So that's an improvement. I'm still taking herbs because I'm prone to getting infections. And then when we had the wildfires I was pretty sick after that because of the air. But yeah, I mean, I'm still taking medication but not to the extent that I was in the very beginning where I was taking I don't know how many all at once. And now I'm just maybe on a few herbs to help with whatever, if I come down with a cold or a virus or something, and that's pretty much it. And then with the chemical sensitivities, it's avoidance and making modifications on what I wear and what products I use.

BLACK: What treatments would you say have worked for you and what hasn't? And by "treatments" I mean ones prescribed by both your Chinese medicine physician and then your MCS physician.

ILAGAN: Well, if it's for chronic fatigue and things related to chronic fatigue, my MD prescribed naltrexone, that's for autoimmunity issues. And that helped me a lot. And also methylcobalamin, because that has to do with the way I detox chemicals in my body. So those two pharmaceuticals help. Other herbs, let's see— Oh, I also took an oral magnesium that helps with the muscle aches and pains, and topical magnesium. For herbs, I'm always prescribed like ten or twelve herbs at a time and they're Chinese herbs, I can't say for sure what they are. And they would they would always vary depending on you know, whatever infection I'm fighting, so but I know those three for sure has helped me now: naltrexone, methylcobalamin, and magnesium.

[00:43:21]

BLACK: So, does your Chinese medicine physician and your MD for your chronic fatigue, do they know of each other? And are they pretty supportive of each other?

ILAGAN: Yes, I let them know what the other is doing. The MD will prescribe something to me and then I would take it to my Chinese medical or Chinese medicine practitioner and she would test it on me. And she would fine-tune it. So they do work together. I mean, I've had to change my practitioners because sometimes—I had one doctor who felt threatened by the Chinese medicine practice so I couldn't—I wanted them to work together because the Chinese medicine or the herbs were helping me and her approach was helping so I wanted them to work together.

[00:44:37]

BLACK: Is there one branch of healthcare had been most helpful with your MCS, since you've had to shop around for MDs who were willing to work with your Chinese medicine physician?

ILAGAN: What helped the most? I guess, initially, the Chinese medicine helped me on the path to recovery. And then when I started seeing the integrative MD that helped me cover the other bases, like doing the genetic testing. So, I guess, initially, Chinese medicine and then integrative medicine.

BLACK: I'm actually also curious, so do you turn to creative outlet for coping with your chemical sensitivity at all?

ILAGAN: Do I— I'm sorry? Do I—?

BLACK: Do you turn to any creative outlets for coping with your illness and your chemical sensitivity?

ILAGAN: It's mostly been writing. Writing is my outlet.

BLACK: What kind of writings do you do? Is it creative or is it editorial?

ILAGAN: I guess, personal essay. I had this idea—it's still something that I need to spend some more time in, but writing a book on— There's other gifts that that came about from getting ill like—what do you call it?—with increased sensitivity I also became psychically sensitive, if that make sense. So I was going to write about that. And then also maybe write a children's book to explain chronic fatigue syndrome and MCS. It's mostly been writing, that's been my main creative outlet.

[00:46:58]

BLACK: What are the strategies for getting any accommodations that you need?

ILAGAN: Could you could you repeat that?

BLACK: Sure. What are some of your strategies for getting the accommodations that you need?

ILAGAN: For MCS, or for both? For CFS?

BLACK: For both.

ILAGAN: At work—when I applied for this job, I let them know that I have a history of chronic fatigue syndrome. And then there's times when I've had extended time away from work from for being sick, so they're aware of it. It's mostly that. I was just upfront with whoever I worked with, either if it's a short job or with this one where I'm working twenty hours a week. They know that I had that history, so I'm kind of more prone to when I get sick, sometimes it hits me harder than most and then I'll have to take time off work. And then Solve, this CFS nonprofit, they know about my illness, so they know if I can't produce anything on a certain day, and then I'm having a flare, they're accommodating that way.

BLACK: How would you say chemical sensitivities in combination with your chronic fatigue affect your life the most?

ILAGAN: How does it affect—? Or what—? In what way does it affect my life?

BLACK: Yeah, the most, would you say?

ILAGAN: I'm not sure how to answer that. You mean, how it's changed my daily life?

BLACK: Yes. Just in thinking of how this is an onset of you being diagnosed in your late thirties and early forties.

[00:49:18]

ILAGAN: It's changed so many aspects of my life. My working life is changed. And it also made me think about what I want to do. It fine-tuned what I want to do with my life. I know that talking about the illness is going to be part of that. Also, in finding a life partner, although that's not a priority at the moment, but in the future, I'd like to be with someone who either knows about it or recovered from it. What else? Also, it influences where I decide to live. I do better when I'm near the coastal area. So, at some point, I'm going to hopefully move back there because my health is better when I'm by the ocean. I think those are the main areas that it's affected me. It affected me financially, too, because after I got ill, everything that I had is all thrown into getting better and trying to find treatments. So, yeah, I don't think there's any part of my life that it hasn't affected.

BLACK: Where is it that you currently live now?

ILAGAN: I stay with my mom because she has dementia. And my dad has several camper vans and trailers and then I tried staying in that. It was okay for a while, but with the heavy rains, it doesn't dry completely. And I'll get sensitive to mold or whatever is left over from the rain. So it's not a perfect solution. And I've been thinking about maybe getting a tiny house or something and putting that near the ocean. Because I've struggled, too, with finding housing. I would jump from one apartment to another and then I would find out later, maybe a day later or even a few hours later that I'm reacting to something in that place. So, I'd have to move again. That was kind of my history from the last year or year and a half. Right now, I'm just kind of on standby at my parents' where I'm helping my mom. And I have this temporary situation, to try to manage the sensitivity as best I can.

BLACK: Can you describe what that's like, actually? Helping to take care of your mom while trying—?

ILAGAN: —Along with—

BLACK: —Right.

[00:52:24]

ILAGAN: —Yeah, it's not easy. Because there's days when we're both feeling sick. So like, “Okay, Mom, I don't think we're going to do much today, other than nap.” But I enjoy it. I like helping my mom with her cognitive—I'm trying to—what do you call it?—do cognitive stimulating activities with her. And that's part of what I do at work, too. I mean, they have—I help at this apartment building. They are seniors, but they are all independent but some of them have the beginning stages of dementia. I do similar activities with them as I do with my mom. It's kind of tricky, also, because there's certain rooms in the house that I know that will affect me. I don't know how to explain that. Because there's things that are left and there's people in and out. So sometimes I won't go inside the house. And I'll just meet my mom outside where there's fresher air. It's just a little odd. But we just work around each other's limitations.

BLACK: Well, Rowena, we are getting close to the hour mark. Is there anything that we haven't talked about that you would like to mention?

ILAGAN: I touched on it a little bit with the housing situation. There's a lot of people with chemical sensitivities that are going through that, jumping from house to house and not having a really set place to go. And it's hard to just go into an apartment building or an apartment and see if that that place is going to be okay with you. So, I think a lot of people are struggling with housing too and it's not something that you hear about. But we're among the homeless, too, by accident because of our chemical sensitivities.

BLACK: And would you say this is your current activism project that you're working on?

[00:54:46]

ILAGAN: Yeah, I think it's going to be something that's on my mind now, because this has to be addressed, because there's a lot of people, also, that are struggling with housing. And then how do you explain— There's already, it's not always positively received either, but it's hard enough to explain something that not a lot of people are aware about. And then you throw the homelessness issue in it that people are divided over. It's kind of hard to gain support from that. But I think that that's probably another issue that people with chemical sensitivities are going to advocate for, proper housing. I know they tried to have proper housing for the chemically sensitive up in Northern California, but they tried to have them all in this one apartment building, and it was a flop. I think the best way to house the chemically sensitive is to have these tiny homes that have materials that don't off-gas, and they don't retain moisture so mold isn't an issue. So, it's going have to be custom made, but maybe an organization will come along that will help the chemically sensitive to have these tiny houses. But that's a goal to shoot for, I guess.

BLACK: Yes, hopefully. So, I just want to thank you very much for taking the time out of your busy schedule to help us with this project.

ILAGAN: Oh, my pleasure, my pleasure. I hope that was clear.

BLACK: Yeah, absolutely.

(End of June 14, 2019 interview)