Oral History with Ash Farnan

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Interview of Ash Farnan

SESSION 1 (4/24/2020)

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(Pre-interview greetings and discussion of interview process.)

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YIU: So, to get started, I wanted to get to know who you are. I know that you're living in Los Angeles now. Can you tell us when and where you were born?

FARNAN: I was born in Riverside. So, Inland Empire, Southern California—suburbs in 1987.

YIU: What was it like then? Did you live in a populated neighborhood?

FARNAN: I lived pretty much in the suburbs throughout my entire childhood. There was definitely a shift in socioeconomic class. Not in my neighborhood—in my early childhood, we ended up moving to a neighborhood (where) most of the residents were of a higher socioeconomic status and so that is the bulk of my memory. But from what—I haven't been back to the neighborhood that I was born in, that I lived in for maybe the first ten years of my life—but from what I understand the neighborhood, it has—there's a fair amount of violence there now. So it's changed a lot, but I don't really have direct memories of that. Any more details you need on that in particular?

YIU: No, that's great. So, you remember this shift and moving. Why did it change? Did your parents change their jobs? What was happening at the time?

FARNAN: Yes, my father took over the company that his father had started. It's a fairly small plumbing contracting company that my grandfather had started. I think that that came with it, or that was a big part of it.

YIU: What did your mum do?

FARNAN: She's been a homemaker.

YIU: Do you have any siblings?

FARNAN: I do. I have three younger sisters, and all pretty much about a year apart. So, very close, age wise.

YIU: And now they're still in Los Angeles or in California?

[00:12:00]

FARNAN: They're all still in (California). Two of them are still in Riverside. The third, my youngest sister, had been in (California) up until about a year ago when she and her family moved to Reno (Nevada).

YIU: That's still not terribly far, I guess.

FARNAN: Yes, they've been able to come back and visit every so often. So, it's good for them. Anybody who can get out of Riverside, I am happy for them.

YIU: Great. So, you're currently enrolled in the master's program in social welfare. Can you tell us a little bit about what you do day to day?

FARNAN: A lot of time on Zoom. I have classes pretty much two full days a week. I'm taking a full course load and then the other two days a week I'm in my internship, which has also transitioned to being remote. And yes, has been a bit frustrating. It started out the beginning of the quarter being good—much better, I would say—in the sense that we were with a Senior Care Center. So, there was a high need to respond to especially homebound seniors with helping them make sure that they were getting their needs met. And things have slowed down a bit. So, the days are less—it's less stimulating, I guess I could say. So, I've been having a little bit of frustration with that, but and then—yes, pretty much—(crosstalk).

YIU: —(cross talk) Yes.

FARNAN: Yes, sorry. Go ahead.

YIU: No, I was just wondering—because I'm also enrolled at UCLA, and the school stuff happening within higher education, about how the pandemic, (2020 COVID-19 pandemic) is shifting how people live from a day to day life. I'm thinking and imagining that living as someone who lives with environmental illnesses, this shift is very different from what they imagined the shift to be. Can you talk a little bit more about that?

FARNAN: Oh my gosh, thank you for saying that. Yes. I'm sure it will come up based on what I think our—I mean, you said the questions have shifted a little bit, but based on what I saw the trajectory of the questions. My relationship with housing is still pretty bad. I still have a pretty hard time being indoors and still have not been able to find housing that makes me not feel ill, so it's been very tricky. I spend a lot of time outside and so it's—juggling. Going to—being in Zoom classes or doing all of these activities outside is a different experience than just—yes.

[00:15:21]

YIU: Yes. I know that, of course, your experience, everyone's experiences with environmental illness is different, but some folks experience electromagnetic sensitivity.

FARNAN: Yes.

YIU: So, participating on Zoom, have you had difficulties in that?

FARNAN: Yes, that's such a good question. I don't think that's ever been a significant component of my experience and I don't know if that's just because I'm also very aware of the stories that my mind tells myself—that tells me about what is relevant to my experience. So, I think the electromagnetic sensitivity thing like—I never really allowed it to enter my consciousness as a potential factor because I think I was afraid that it would then become another source of obsession. So, I have compartmentalized the possibility that that is a factor in my experience. I do think that I am, but it doesn't seem to me to be a critical component of my sensitivity.

YIU: Yes, I mean, earlier you mentioned that even though it's next to you, it's very difficult to accept it because of what it means to accepts it. Can you talk more about your experience of how you have come to discover your sensitivity?

FARNAN: Sure. I moved to Seattle (Washington) in—it would have been around this time, around late April of—oh my gosh, I get the year mixed up—2017, I think it was. Yes. I moved into a house with a few other roommates and it was a pretty old, not super well taken care of house. I didn't have any furniture or anything—I moved from Baltimore (Maryland). My roommate very kindly lent me a spare mattress. For the next six weeks, I was also primarily working from home during that time because the nonprofit that I had moved to work for hadn't yet gotten an office. So the next six weeks were this crazy, mind cycle—excuse my language, but it was just like every system in my body was going haywire, mentally and physically. My temperature was so dysregulated. It was springtime, it was pretty warm, (but) I was so cold all the time. I felt like I was on the verge of a panic attack all the time. I would wake up in the middle of the night with these insane night sweats. I would just be drenched, and my body hurt. I was just tired all the time. Seattle's super hilly—I probably would have already (had) an issue, but I would walk for a little bit and I would be winded. My digestive system was completely out of whack. I had no idea what was going on. I don't think I was really trying to—I wasn't really putting the puzzle pieces together. I just knew I felt like crap.

Then I spoke with a friend who lives in Portland (Oregon), and they've lived in Portland for a long time. They—I don't even know what their experience—we must have had this conversation, but I can't remember what their experience with mold would have been that they would have even thought to raise this as a possibility, but they said like, "I wonder if something could be moldy." Then I started down the rabbit hole of internet searching and saw that my symptoms could tick almost every box. Then I went to talk to my roommates about it and learned that the mattress that I had been sleeping on had been stored in the basement over the winter and the basement flooded and the mat- they never properly dried out the mattress, it just sat in the basement. It's a Seattle basement anyways, so nothing dries out in Seattle to begin with. So, I never actually got the mattress tested. This is all just like—these are all assumptions. But the house was also—there were wet spots on the ceiling, so I felt like it was pretty valid that I could make that conclusion that there was mold in the house. Yes, so I feel like now that I have become more immersed in awareness of other people's experiences of this, I feel so, so insanely lucky at how quickly I was able to put the puzzle pieces together. Because I'm so aware of the people who spent years, decades of their lives sick all the time, and not understanding what's going on. So that was how I figured it out. After I realized that, I started thinking back to a few

past experiences that I had had where it seems pretty clear that that was probably what was going on.

[00:21:08]

YIU: Yes, wow. So, you were—it was 2017 in Seattle. How old were you at the time?

FARNAN: Oh, gosh, you're going to ask me to do math.

YIU: Oh, maybe I should do it.

FARNAN: Let's see, well, this should be pretty easy to figure out, right? If I was born in 1987—

YIU: —You should've been thirty.

FARNAN: Yes. Yes, right? Yes.

YIU: Yes. So you were thirty at the time, working at home for an NGO (non-governmental organization) you were saying and so you were experiencing these symptoms and until you talked to your friend in Portland, you did not know what was happening?

FARNAN: No, I didn't.

YIU: And how long was that process between you experiencing the symptoms and talking to your friend about it?

[00:21:59]

FARNAN: I think it was probably about six weeks. I think maybe what happened is the physical symptoms were ramping up, but it wasn't maybe until the last week or two of that period that the panic started to increase. I think that was maybe what started to really—because I've had also a prior history of my body being not great. I studied abroad in East Africa as an undergrad, and I was sick with malaria a lot, and my body just never really fully rebounded after that. I think I also just had—like I move through life now with the assumption that my body is going to be unpredictable. So that may have been why the typical symptoms—I mean, yes, the night sweats were weird, but I would say it was probably about six weeks until I talked to them about it.

YIU: Yes. And so, as the time what did you make of your symptoms? Were you frustrated? What was your experience like?

FARNAN: It's weird. It's hard to—I don't know if I repressed this or something. I think this is connected to what the psychological process has been for me through this and the—I don't know—the positive psychological things that have come out of this whole experience. I think that I used to be fairly disconnected from my body. If I felt l unpleasant bodily sensations, I think that there wasn't like—I had the mental ability to with mental brute force, compartmentalize it. So I almost have a memory of—I just remember I just kept like drinking more coffee and forcing

myself through it. It's almost like I wasn't fully like—I was feeling it, obviously, because I felt like crap. But I think the ability to mentally reflect on what it felt like to feel that way, I think I can't quite access that because I don't think I was fully there for it in that way, if that makes any sense. I think once I started—once a potential source was identified, then it very quickly became fear and obsession. But you're asking about like the period before I found out, right?

YIU: Yes, I think it's interesting to note the transition of how you were feeling between these feelings of perhaps, denial, as a survival tactic to continue on, into a shift of fear where you were doing consistent research about why you were feeling this way. So I think it does make sense. When you did discover that it was the mattress, what things did you do after that? You got rid of the mattress and—

FARNAN: Yes, I talked to my roommates about it and I have a weird relationship with the woman who owned the house, who lived there as well. It was a little bit —not mentally, I won't say mentally unstable, emotionally unstable and so there was tension around my talking to her about the fact that she—not in a blaming way, she didn't lend me this mattress with any malicious intent, and also the house was clearly not in good condition. So, I talked to her about that, and then I moved into the backyard and started looking for another place to live. I think I hadn't—I think at that point I was still living under the assumption that this is just an isolated incident, once I get out of this house I can move on. So, I don't think the fear had started to grip me as intensely because I thought that there was an escape. I moved into the backyard and started feeling a good bit better pretty quickly after I started—luckily all of this coincided with this incredible Seattle summer of almost no rain. So, it was what was evolved. Yes, exactly.

[00:27:32]

YIU: It’s unheard of, basically.

FARNAN: Pretty much, yes. I mean, it probably has negative implications for what’s happening in Seattle.

YIU: Yes. How long were you living in the backyard and what was that experience like?

FARNAN: So, I started living in the backyard and then started looking for another place. Found another place, moved in, very quickly started feeling sick again. And it started to dawn on me like, “Okay, this is more than just one place.” And so, move—luckily, I was friends with this woman at that original house, so she was willing to let me continue sleeping in her backyard. So, I moved again. And then I moved again. I lived in Seattle for about seven months and I moved six times—lost a lot of money in the process. Most of that time was paying rent on places and sleeping in my friend's backyard. There was one period where I was renting a tiny little studio apartment that had a balcony, and so I was sleeping on the balcony for a while. So, I continued mostly sleeping in my friend's backyard for most of that period.

YIU: What was that experience like—talking to your friends, even to be able to sleep in the backyard? Was it an experience where your friends helped accommodate for you? Was it a difficult conversation?

FARNAN: Yes, this is where I just feel I've just been so lucky. People didn't really treat me like I was crazy. Even my boss—I don't really know what she thinks in the back of her mind, but it seems that she believes me. So yes, my friend was and maybe this is part of the—she was just an interesting, very open minded person and so I think some people also had this idea of like, "Okay, you're sleeping outside, that's kind of cool—like, weird but so." She was—this particular friend was—she's a very generous person. She was—I don't want to make any assumptions—you sound like you maybe have an Australian accent?

YIU: Yes, I'm actually from Hong Kong, so I think it's just the colonial education mixed with moving around. It's very hard to decipher.

FARNAN: Wow, interesting. Oh my gosh, I'm so sorry for making that assumption.

YIU: Oh, not at all. It's closer than what most people guess, for sure.

[00:30:51]

FARNAN: What do most people guess?

YIU: British? Yes, which is like, I guess that's right. But I think I sound more Australian if we were to think about it—but was this friend Australian?

FARNAN: She's Australian. Yes.

YIU: Oh, I see.

FARNAN: Yes. And she's just like—I've just had such consistently lovely experiences with Australians. So I feel like inclined to—yes. But yes, she was very accommodating. She was just––I mean, like, I would go do my life—I mean, she even offered to let me use the kitchen and stuff, even if I wasn't living there. I would have my life in my apartment. I would have my stuff there. I would eat there. Then at night, I would take the bus to the different part of town and I would just creep into her backyard, and she was pretty cool about it. So, I was very lucky in that, yes.

YIU: Yes, I think it's really beautiful to hear the ways in which you have so much gratitude for your friendship, but also in your giggles, you're using humor as a way of moving through this experience. But I'm guessing it must have been difficult to be thirty years old and thinking it's an isolated incident, into having to live in the backyard. And you said that you lost a lot of money. So, in reflecting on that experience, how do you think it affected you at that time? And also, if you weren't financially stable, what did you think? How would you think that was different?

FARNAN: Yes. Yes, it was horrible. It was horrible. I mean, there was another component of it as well that intersected in the timeline that I think also helped to make it less brutally excruciating than it otherwise would have been, which is that I—I wouldn't call it a relationship, that I met somebody around the same time. And there was actually a period where—so this

person actually moved into the room that I had, the moldy room that I had moved out of. So, we overlapped when I was sleeping in the backyard, and she was sleeping in the room that I had vacated. And so, there was a period where she would even sometimes sleep outside in the backyard with me. So, I think that the energy of that helped to make it less catastrophic then—or I guess it distracted me, I guess, in some ways. But yes, I mean, I would say like this, I mean, the panic of—I'm remembering in particular, the first move that I made after I moved out of that house. I moved into the new place and was so hopeful like, "This is going to work." And after a couple of days of realizing that it wasn't working, and I remember just the panic of like, "What am I going to do?" This isn't a matter of not having the money to find a place to live, like every place became suspect, like every—it just escalated so quickly. And knowing this is Seattle, like the reality is everything is moldy in Seattle. There's no way for it not to be.

I think just feeling the panic of not knowing what I was going to do or where I was going to go and trying to spend as much time outside. I would just go to the park after work, and stay in the park until ten o'clock at night. I would go to places— my awareness of homelessness, I guess in a more thorough way, became more heightened because I would—and obviously my reasons for housing displacement were not financial so I wouldn't deign to compare myself to somebody who's experienced it, who is unhoused in that way. But I would start to notice people who would have their—like, "Oh, this person is at the Whole Foods patio from this time to this time. And then they go to this Starbucks probably because they can access a bathroom or they can whatever." I started noticing people's routes. We would notice each other. I guess I started becoming more aware of the thing—the complicated ways in which people who don't have a place to go would try to find the place to be. I would spend a lot of time walking around trying to find a Starbucks where I could use their bathroom without having to buy something. So, it was on my mind a lot of the time and just feeling like in general, I still wasn't feeling well, often. I felt like my capacity to do work—my work was decreasing and so that was stressful. And yes, that was a very long-winded—I don't know if I even answered your question.

[00:37:01]

YIU: No, you did. If you're in need of an affirmation, you're doing so great in terms of telling your narrative in a clear way and you're obviously critically interrogating these structures of displacement. So I was really interested in—by your discussion of your experience of homelessness that's different from financial homelessness, but in the sense that you felt like you, in a sense, shared with those folks—you don't have a place to go and you're finding a place to go where you feel safe enough. So, I was wondering, identifying as genderqueer, what was that experience of navigating from place to place like?

FARNAN: I don't feel like that had a significant bearing on my experience. At that particular time, I wasn't yet identifying as genderqueer. I was still identifying as female. I think also it being Seattle, it was a very—relatively friendly environment in which to present as a gender non-conforming person. I never felt unsafe, or—I mean, if I would be in the park at night and it was getting very dark, maybe a little bit but not because of—I mean, just in general, not because I felt any direct threat. But no, I don't feel that that had a strong bearing on my experience of that time.

YIU: Yes, I was also wondering, you were talking about having this person that slept with you from time to time in terms of just being physically present.

FARNAN: Yes.

YIU: And it made the situation less catastrophic and distracted you in some senses. So, I was just wondering this person, how did you talk to them about your experience of symptoms? Because at that time, I'm guessing you weren't thinking it was an illness in a particular sense.

FARNAN: I think—well, that relationship crashed and burned quickly. She was pretty self-absorbed. She was also in a very intense period of chaos. So her—many, many aspects of her life had been thrown into upheaval as part of what preceded her moving into this house. So I think the upheaval of her life took center stage in this situation, so I don't think we really—we would joke about it kind of, but we didn't really spend a lot of time processing my experience of it. It was just something that was present. But wasn't like—we didn't dig into it, I would say, yes.

[00:40:39]

YIU: Right, yes, who did you talk to then?

FARNAN: Who did I talk to? I think I was pretty isolated at that time, socially. I mean, I had just moved to Seattle, so I didn't really know anybody. And I was like—yes.

YIU: Did you have any mental health support at the time? Or what were some of your coping mechanisms?

FARNAN: It's weird because now that I'm thinking—so I've had a relationship with a therapist for about ten years. She's in Massachusetts. We've not maintained consistent contacts, but I do—she's probably the most significant figure in my life. But I didn't reach out to her at that time and I don't know why I didn't. I started looking for therapists in Seattle. I think part of it is just that I would—I was wanting to talk to somebody who was also physically present. I was seeing a therapist for a couple of weeks and they're just—it wasn't a click there. So, I think he was aware that this was happening in my life, but I think there was another issue that was taking precedence in my existential issues, so that was more of what we focused on. I don't think I really in depth processed that with anybody. I think a lot of people in my life were aware that it was happening, but I was mostly—yes, I don't think I was really processing it deeply with anybody.

YIU: Yes. I know that you were working from home for an NGO at the time while you were experiencing symptoms. How did it affect your work at the time?

FARNAN: I feel like it really affected my ability to focus. Both because I feel—I don't know, I know you can't really make this distinction—but physically, my ability to focus was impacted. And then also, I just felt really physically tired and fatigued and—but then also, I think just this situation, this problem was just running in the back of my mind, constantly so also that was always drawing my attention away. I talked to my boss about it. The nonprofit I was working for was an—it's a nonprofit focused on training educators and parents on trauma informed practices.

So, the most, I would say, emotionally—I don't know—receptive group of people that I had ever worked with. I talked to my boss about it at various points, and I don't think she—I mean, she was constantly expressing her satisfaction with my work. So, I don't think anybody outside of me would have necessarily said that it impacted my work. But it definitely felt like my ability to be engaged in my work was compromised. So, I guess more of a subjective experience of not performing well rather than something that was affirmed from the outside.

[00:45:17]

YIU: And I know you mentioned about your boss believing you and didn't have any critiques of your "productivity," but did you still, and you—however, you still felt a certain type of way. Can you talk about that more of your internal emotional process of this shift in your energy?

FARNAN: I mean, I think that this is where it was like this was another one of the forced, psychological healing aspects of this—is that I think I really was an extremely, I was so perfectionistic and so type A and rigid and constantly perceiving myself as not performing well enough or not being good enough. I think this really got at all of those narratives because I think I was constantly feeling like I just can't—I'm not, I can't be perfect—like I can't perform as well. So that was like—I mean, I would say that the healing had happened in retrospect. At the time it was just like, "Oh my god, I'm a failure for not being able to perform at maximum capacity." So, I think it was very uncomfortable. It was, yes—I got all those I'm a failure, I'm not performing narrative. Yes.

YIU: Did you ask for accommodations at work at the time?

FARNAN: No. I mean, they were very flexible in terms of—like if I needed to go to doctor's appointments or things like that, they were totally fine with it. Ultimately, they gave me the most incredible accommodation that could ever be asked for, which is that finally it got to the point where I moved again for the sixth time and it wasn't working. I had told myself before that, and it was starting to shift into the fall, so it was starting to get rainy. I told myself, "If this move doesn't work, I need to leave. I can't stay here. I can't be sleeping outside in the same way if it's raining all the time. This is going to have to change." And so, I moved again, and it wasn't working. It became clear that I need to leave and if that means I need to quit my job then so be it. I'm going to have to deal with it. And so I talked to my boss about it, and at the time, I framed it as I'm going to go home to—I'm going to go back to Southern California and just try to be in a less moldy environment and heal. See if I can heal somewhat, and maybe I can come back was kind of the way it was framed. And so, she allowed me to do that and let me move and work from home. And then it just continued, and she let me—it worked out. I ended up continuing to work for them for another year and a half or so remotely.

YIU: Wow.

FARNAN: I know. I know. And it was inconvenient for them.

YIU: Yes. How do you feel about that accommodation that they have made?

[00:49:39]

FARNAN: I think I felt a lot of shame about it. I mean, obviously, it was stunning and deep gratitude. It was hard for me to wrap my mind around their generosity and being willing to do that, but I think that very quickly tapped into a shame narrative. I already felt so ashamed about the whole situation, like not knowing—they didn't treat me like I was crazy, but I know I sounded crazy. I didn't—like who knows in the back of their mind what they thought. I think just feeling like I'm—they're giving me this accommodation for this weird thing that nobody else is experiencing and from the outside, I know that most people's first assumption is like, "Okay, this is some kind of psychosomatic thing," which I'm not denying the fact that there might be elements of that involved in it. So feeling like it was an illegitimate thing to be asking for an accommodation about, so I think I felt that and I think I felt a sense—it got to my sense of my own worthiness of like, "I don't deserve this. I'm not good enough for them to be willing to take on the inconvenience that this is causing them." I think I just I never shook that feeling despite constant validation that if it wasn't working out, then they wouldn't do it.

YIU: Yes, that must be a difficult field of emotions to be navigating. How would you advise others to navigate these emotions?

FARNAN: I feel like this is where you can't separate your emotions from the—I mean, I'm feeling my social work person and environment hat come in. I had so much support. I had a father who was willing to let me come move back into his house. I had the financial resources—I knew I wasn't going to end up on the streets. I had doctors who—I pretty quickly found doctors who validated my experience. I feel like the resources that I had available to me had such a bearing on my ability to navigate the emotions. I can't imagine what it would be like for somebody who really, their only option was to sleep in their car, or not be able to—for me, it was like, "I can quit my job if it comes to me having to quit my job. I know I can move in with my dad and he's not going to kick me out." I know a lot of people don't have that luxury so I think I'm just aware of the way that my privilege has enabled me to navigate the emotions of the situation.

So, I don't know how to generalize an answer to that—also the mental health support that I had. I did eventually end up—shortly after I left Seattle—I reconnected with my therapist from Massachusetts, who has been one of the most critical components of my ability to reframe and heal from this whole thing. Having her on my side, I would say, yes—I mean, after I moved back from Seattle, it was a dark period of mental health. There was a pretty—I've struggled with suicidal ideation for a long time and there was a period where it got pretty serious. She—so I think having the mental health support to navigate that was also what got me through it. And so, I don't know. I feel like the answer to how to navigate the emotions is like, "Be lucky enough to have the resources to navigate the emotions." I don't—like, luck. I don't know. I know it's more complex than that, but that's what stands out to me.

YIU: Yes, I think that's great because it shows how difficult it is to predict the unpredictable, that you have also talked about earlier. When you did bring up environmental illness or how it impacts your daily life to the therapist in Massachusetts, how did you bring it up? And how did they respond?

[00:54:42]

FARNAN: I think by the time I reached out to her, I had already started—so are you familiar with, and I would be curious to know if there are others who you have spoken with who have done this—but with the various neural retraining programs that are out there for people with chronic illness?

YIU: Yes, I have heard of them talk about it.

FARNAN: Okay. So, one of the naturopaths that I had been seeing had recommended to me that I work with one of these programs. And the one that I ended up working with is called the dynamic DNRS; the dynamic neural retraining system. I would say it's one of the two prominent ones and I did it. It was an online—it was like, I ordered the disc, so I didn't do an in person workshop with her. And so that like was—that very quickly helped me, or it gave me the lens of looking at this also as a limbic system trauma. Yes, what I experienced was real—I really am sensitive. And my brain has been so hyper sensitized to this that maybe I'm picking up on things in the environment that are possibly in quite miniscule amounts that others wouldn't be sensitive to. I'm picking up on them and my brain is going into hyperdrive and helping to instigate this cascade of physiological responses to it. So, I think I started to reframe it in that way. And I'm constantly straddling the line between—like, I see how quickly that can veer into "This is in your head." And that's so—and I don't think that that's what it is, I think it's far more nuanced than that. But so, I think by the time I started talking to my therapist about it, I had already started framing it that way. So, she never denied that what I was experiencing physically was real, but I think we did work with it and more of a—I don't know—like a mind-body psychodynamic kind of way, generally.

YIU: Can you tell me more about what—is it limbic trauma?

FARNAN: Yes, that's what they call it.

YIU: Can you tell me more about what that is and what arriving to that terminology means to you personally?

FARNAN: I mean, as I understand it, the limbic system is the seat of where the trauma response is for anybody, regardless of the trauma, and that there are different like—I'm sure you know all of this already—there are different ways to conceptualize trauma. And that also exposure to a toxin or to a virus or to something like that can also instigate a trauma response in the brain, where the brain becomes—basically is in that constant fight or flight state where you are just generally more hyper sensitized to your environment because you are aware of the possibility of threat. And so, you're more, maybe attuned to potential triggers than other people would be. What that means to me—I think it makes sense to me because I could see the way my mind would take me down. The way the train of thoughts would get started and then just obliterate me. I think I was aware of the way that my—yes, there's like mind brain. Yes. How did I experience it? I think it was helpful, but I think I did have to constantly straddle the line between this doesn't mean it's all in your head. This is true, and it doesn't mean it's all in your head, I guess. I still feel

very tentative when talking about it to others who are experiencing chronic illness because—yes (crosstalk).

[01:00:04]

YIU: —(crosstalk). Yes, I think that this very difficult line that we're balancing between how environmental illnesses is actually experienced from multiple perspectives and I think that was really wonderful how you explained how you experienced it, but I do want to check in because we've been on the phone for an hour. Would you like to take a short break? I definitely have more questions for you, I'm sorry, but I wanted to talk more about your experiencing those experiences of obtaining healthcare and what that was like. And, obviously being enrolled in a master's program and how it is navigating school life as well. Would it be good if we rescheduled for a different day? Because I know that you do have another call at 12:20, so I do want to give you some time to rest in between.

FARNAN: Yes, thank you for your conscientiousness around that. And also, if I ever—I know you have a list of questions you need to get through so if I ever getting into the weeds about something that isn't quite right, feel free to cut me off because I also recognize that this is your time as well and that you have things you need to hit, so please feel free to give me that feedback (crosstalk)—

YIU: —(crosstalk) No, actually, I haven't at all. Thank you for keeping that in mind. I have not experienced that.

FARNAN: Okay, I'm flexible. I would be fine with rescheduling. I would also be okay with talking a little bit longer today if it's more convenient for you to just come to plow through and do it today, then that's fine or I'd be happy to reschedule. I think in terms of my next call, as long as I'm done by noon-ish, I think would be a comfortable stopping place, but also you have been listening and asking questions for an hour which is exhausting in and of itself.

YIU: No, not at all. I'm having a really great time. And I feel like it's, everyone's links of storytelling and storytelling method is so different when it comes to telling their stories. So, I think I would rather you go into depth more because of the details that you can provide us which is so important to our archive. And it's not a list of things that I have to hit. Every interview is different. And yes, I can certainly continue. Thank you for your energy. But I just wanted to talk more about—you were talking about, you did quickly find healthcare from a medical professional. Yes, when you move back to California, is that right?

[01:03:10]
FARNAN: No, I saw somebody when I was in Seattle. So, even before I moved back to California, I saw somebody.

YIU: Oh, and were they a physician or a naturopath?

FARNAN: He was an MD (medical/allopathic doctor), ND (naturopathic doctor). So he had both, which I think was helpful for me because I think I still had a bit of skepticism around the

legitimacy of naturopathy—is that how you pronounce it? So I think the fact that he wore both hats made me feel a little bit more receptive to potential alternative explanations for what I was experiencing.

YIU: Right. And so, when you went in, how did you find this doctor?

FARNAN: How did I find him? I don't remember how I found him. I mean, at that point, I think I had already started to do research. I was already online, and understanding the mold—like in the mold communities so I wonder if I got him from one of the mold related databases that like he was a mold, mold-friendly doctor. I don't remember.

YIU: Oh, that's okay. What was that experience like though—the first time going in to talk to a medical professional about what you were experiencing?

FARNAN: I remember so he did—what is it called—kinesiology? The muscle testing, you know that?

YIU: Yes. And what happened?

FARNAN: I mean, this is where it was helpful for me that he also had an MD because that to me was like, "What the hell is this?" It was interesting because we hadn't really gone into—I mean, he knew, yes, so, okay, I won't go into all of the details about it but—so he tested me for mold. He also tested me for different kinds of parasites and ended up settling without realizing—he did it in a very, double blind way where he didn't know what he was testing me for, and ended up honing in on one particular malaria parasite, which was very interesting.

YIU: Which you had malaria you were saying.

[01:05:56]

FARNAN: Exactly, yes. Okay. So, but then something that happened that I feel like was one of the most validating things is—so he had this little vial of mold that he was using to test me with. He said that I responded quite strongly to that when he was formally testing me for it. But then near the end of the process—so I was sitting with my back to his desk. What he would do is he would set some of these vials— he would set it on the desk behind me, and then he would test me. He finished testing me and then he sat down next to me and was just talking to me. I started feeling really intense symptoms, and I was like, "What is going on?" He realized that he had just absentmindedly set (the) mold vial right on the desk behind me and it had been sitting there for the ten minutes of our conversation. And so, I don't know, there was something about that. It was like such a distinct—I am reacting to something—what just changed. He realized that that was sitting on the desk behind me and I didn't know it was sitting there.

YIU: Because you were turning your back against it.

FARNAN: Exactly, yes. So, that was pretty validating for me.

YIU: Yes. And so in that experience of being validated that this was not psychosomatic, are you were describing, or not simply psychosomatic. Did he offer you a diagnosis or what happened after that?

FARNAN: He ran the—oh, gosh, I feel like it's been so long since I've talked about this—but there's the whole thing in the mold communities about this HLA-DR (Human Leukocyte Antigen – DR isotype) gene that supposedly makes you more susceptible. He ran the whole spectrum of those blood tests, and all of that, that came back showing that I do in fact have this gene. I don't know how much credence I give that now. At the time it felt validating, now I feel a little bit more like it's neither here nor there. But so he ran those tests and they all came—I mean, they came back pretty strongly, validating all of this so I don't remember if he gave me a formal diagnosis or if he basically just validated that I have very severe mold sensitivity. He may have called it biotoxin illness. I don't quite remember what terminology he used.

YIU: Right. And so, being given that affirmation, how did you feel?

FARNAN: I definitely felt legitimized. I felt like I have something real and medical to point to, to explain this.

YIU: Did it feel like it was sufficient or what were some of the steps that you took after that interaction?

[01:09:20]

FARNAN: Yes, I think that's where it was short-lived in a way because—and I only saw him once more after that—because he just didn't really have anything to offer me. It felt like, I remember going into his office the second time and maybe it was the third time—maybe I saw him three times—and just crying because I had moved again and I was still sick. I remember him just looking at me and not having anything to offer me. I think it felt to me like if the problem is the environment—if I am just sensitive to these environments and there's only so much that you can do to like—you can help me to alleviate the symptoms, which he wasn't—I mean, I don't know how much anybody can even do that. So, I guess I take that back. It felt like there was only so much that medical practitioner can do for me in this situation. He gave me the supplements, but mostly to me, it just seemed like it was about avoidance. I need to avoid the triggers. So then I ended up finding a Portland-based doctor, and I definitely found him through the mold communities because he was like one of the doctors that had actually been trained by Richie Shoemaker. I'm not sure if you've come across his name if you talked to other mold people.

YIU: I've read about Richie.

FARNAN: Okay, okay. So, I saw him (crosstalk)—

YIU: (crosstalk)—And here when you went to this mold doctor.

FARNAN: Yes, yes.

YIU: Was is a different interaction?

FARNAN: With him? Yes. Yes, on all levels, like health wise and just mentally and emotionally. He also like—

YIU: Can you tell me—

FARNAN: Yes, go ahead. Go ahead.

YIU: I was just going to say, can you tell me more about the difference?

FARNAN: He seemed much more emotionally attuned or attuned to the emotional contours of this. I felt like a compassion from him. He also admitted to struggling with mold himself, so I think it may also have caught like—I think that was how he came to the Shoemaker training. He started experiencing it for himself. And I think he had an empathy that was different. I just remember like—I think also, his honing in on the mental processes that exacerbate this in a way that did not feel delegitimizing. At the time, at that point, I was starting to become more sensitive to chemicals. He asked me some questions and he said, "It does sound like you are in the ramp up phase to chemical sensitivity," and that terrified me. And so, then he really dug in. We just were talking about it and that's when he referred me to the Dynamic Neural Retraining System. And he—I don't know. There was just some—there was a different tone to it felt like he saw something more than just the physicality of it that gave me more hope I think than what the other doctor had. Yes.

[01:13:30]

YIU: Right. So, it was the shift in attitude. Did you ever have to advocate for yourself as a patient in receiving that kind of empathy or other things?

FARNAN: This is where I just—I feel how lucky I am. No, I had doctors who believed me.

YIU: You were saying that you were that was the time when you came to this mold specialist that you were becoming more and more sensitive to chemicals. What were some chemicals that you remember becoming sensitive to that you weren't sensitive to before?

FARNAN: Yes. The usual—perfume or cologne, dryer sheets. If I would be walking around the neighborhood and I would pass by a house where somebody had the dryer running, I could smell it from across the street. Detergent, scented candles. I was living with my dad at the time—he would have his house cleaned every two weeks and he's definitely not somebody who's interested in using environmentally friendly, non-toxic products. So, it was—I would come back to his house after the house having been cleaned and it was pretty awful. And food sensitivity, I became sensitive to like seventy-five percent of foods as well.

YIU: Wow, that must have been a huge change in life. Did you use anything to alleviate your symptoms now, like herbs or anything like that?

FARNAN: Like what?

YIU: Like herbs or solubles or—

FARNAN: I have such a weird relationship to—no, I guess, is the short answer. I've experimented a little bit with herbs. My therapist definitely—I won't say she pushes herbs, that sounds aggressive—but she definitely thinks that they would be helpful. But it's never really been something that I've been able to fully internalize as something that would work. I've never been able to surmount that mental block.

[01:16:31]

YIU: So other than avoidance, how do you alleviate your symptoms in day to day life?

FARNAN: I mean, I would say in general, my symptoms on a day to day are significantly better than they were a year, a year and a half ago. So I mean, obviously, depending on if I'm going to––yes, I guess yes and no because if I'm in a building like it's (crosstalk)—

YIU: —(crosstalk) Yes, oh sorry, how did that shift occur?

FARNAN: I would say the first big step was the working with the Dynamic Neural Retraining Program. And the well, it's the—I do a dance practice now that I would say has pretty much saved my life.

YIU: Wow. What is this dance practice?

FARNAN: Well my teacher, when I first started dancing with her, she was teaching in the—have you heard of the 5Rhythms?

YIU: No, I have not.

FARNAN: It's a conscious dance practice. And it's—I mean, it looks pretty crazy from the outside. It's basically just about—like all of the mirrors are covered. It's not about what you look like. It's not about learning choreographed moves. It's basically just about moving your body as spontaneously as you can in a room full of other adults who are also doing that. It's been very powerful for me to move this stuck stuff that has been stuck. So, I think that helped. There are other things I think that helped indirectly. I feel like the answers to your question aren't physical. They're not—I don't know—like they're things I feel like that got at unraveling the rigidity of the way that I had been living my life like, loosening, yes. I don't really have more cut-and-dry—yes.

YIU: No, I think that that actually leads me to my question about what are some of the hobbies that now you take on, and has your sensitivity changed the ways in which you do your hobbies now?

FARNAN: Yes, I would say this dance practice. I mean, obviously it's changed now that we're quarantined. But yes, that had a really big impact and it has also connected me to a community as well. My teacher has been, a very powerful presence in my life and the others, yes—I feel like it's the first time I've ever done something that I really loved doing and feeling good in my body, actually realizing I had a body, too. So that, and seeing outside more, I guess. Doing more hiking and camping and those kinds of things have been helpful.

[01:21:03]

YIU: Yes, you were talking about the experience of—maybe not returning—but the experience of having a body again. What was that like?

FARNAN: I think it was painful at first. I feel like I had to go through the—if I look at the possibly metaphorical ways of looking at all of this—the physical distress of being sick, really forced me back into my body. I feel like it started forcing me to have to advocate for myself in certain contexts where in order—if I would be going to look for a new apartment or something, I would have to ask the landlord like, "Can I sleep here for a night to see how my body feels?" I started having to make inconvenient requests to accommodate my body. So, I think it was painful at first. I had to learn that lesson. Pain was the only thing that could get my attention. And then I think through the dance practice, I've found that actually there can be pleasure and joy in being in the body, which is a pretty mind boggling.

YIU: Wow, that sounds like a huge difference it made in negotiating those feelings. You mentioned earlier that when you moved back to California, your dad cleaned the house every two weeks or did he hire someone? I don't know.

FARNAN: He hired someone, yes.

YIU: Yes. Did you ever have a negotiation of changing the products that he was using? You said he was—

FARNAN: No. No, he would never ever, ever consider that. No.

YIU: Why? Why do you think that you were feeling like you shouldn't mention?

FARNAN: I mean, I think that I probably mentioned—I know that I've mentioned to him like, "This is very toxic. It's not good for you," like in that kind of a way. I would never consider making that request just because I don't think—I mean, first of all, he's very set in his ways. I've spent ten years trying to convince him to not use plastic water bottles and he just doesn't get it—like he doesn't. So I just—I knew it was futile. But I think I also have this like—it's made me see this—I considered myself to be a pretty environmentally-aware person prior to this whole experience, but I didn't really—I knew that it was better to buy non-toxic products, but I didn't always do it.

I don't think I had that same embodied understanding of what toxicity did both to our body and the earth body. I was sort of dissociated from it. It was something I did because I was supposed

to do it, not because I deeply felt like it needed to be done. I think it gives me a little bit more understanding for people who—I don't know, there's something about needing to really experience it that intimately to have an embodied understanding of what we are doing to the planet and ourselves by perpetuating this toxicity. And I think the connection to bodily disconnection—I look at dad, for example, and I see how disconnected he is from his body. I see the pattern between people who aren't in their bodies aren't necessarily going to understand the importance of preserving the earth. I see the connection.

[01:25:17]

YIU: Yes. Before we move to talking about this embodied understanding of what toxins does to both your body and the earth body, I wanted to ask if your experience of chemical sensitivity shifted your family relations?

FARNAN: Well, my mom definitely has this. She's not ever seen a doctor about it, but I think she has it almost even worse than I do, and has been sick for a very long time and now actually is like—so anyway, I won't go into the long details of that. But so I think that she understood it and was willing to really believe it in a different way. I don't know to what extent she connected it directly to her own experience, but I think that there is an inclination to believe or something. My other family members, I think we don't really talk about it that much, which is representative of our relationship in general. So, I don't know what they think about it. Yes, we don't really talk about it that much.

YIU: Yes. Do you think it affects your relationship with your friends or your co-workers or who you date or how you date, for example?

FARNAN: I definitely am very, very wary about who I talk to about it. I have to suss out beforehand that you are going to be somebody who's going to be open to it before I'm willing to like—it feels almost like something I have to come out of the closet about. It feels like that. So I recently talked to a friend, who is another person in the MSW (Master of Social Work) cohort, and we were talking about it a little bit because I had just moved into a new house and was starting to feel sick. And so, I was in the middle of the panic about that, and I made the mistake of talking to them about it. The first sentence out of their mouth was, “Don't you think this was probably psychosomatic?” And just the like—I can't really—our friendship has shifted since then. I'm not—I can't. Also, they're in training to be a therapist. They have things to learn clearly —

YIU: Yes, that's terrible. I'm sorry that they made such a big presumption. I know that it's almost twelve. And unfortunately, I don't think that the question I have left will be answered in ten minutes. So, I'm hoping that it's okay that we pause it for today. Can we schedule a time perhaps now or later via the email to perhaps schedule a follow up interview where—I think I just have some questions about navigating school, how do you live financially, having had sensitivities and as well as perhaps online communities whether the mold community or the MCS community that you're aligned with?

[01:29:17]

FARNAN: Okay. Yes, sure, I would be happy to reschedule.

YIU: Thank you, and would you be free to schedule now, or do you want to wait a little bit to look at your schedule?

FARNAN: No, we can schedule now. I'll just go look at my calendar.

YIU: Let me know when you're ready.

FARNAN: Okay. Okay, so I mean, I guess I probably could have just said this before without even looking at my calendar. Fridays in general would be best for me. I can't do Tuesdays or Thursdays, and Mondays or Wednesdays I would need to be in the late afternoon or evening. But Fridays in general are pretty open for me.

YIU: Okay, thank you. Because I do want to keep continuity at best, would it be possible that we speak on Monday, the 27th in late afternoon time, would that work for you? It should be under forty-five minutes, I'm hoping.

FARNAN: Okay. Yes, that would work.

YIU: What would be a good time on the 27th, Ash?

FARNAN: After five would probably be ideal, but after four would be doable.

YIU: Okay, why don't we say five p.m. then? So, you have some time to decompress and whatnot.

FARNAN: Okay.

[01:31:31]

YIU: You can definitely email me if that day something changes as well.

FARNAN: Okay. Yes, I think it should work. Great.

YIU: Okay, well, I look forward to speaking with you on April 27th at five pm. Thank you so much for your time and your generous energy today, Ash.

FARNAN: Thank you for your thoughtful questions and your kindness and your listening. You're a very good interviewer.

YIU: Thank you. That's so kind of you. I can't wait to talk more with you. Good luck with your week and have a good weekend.

FARNAN: Yes, you too. Take care.

YIU: Thank you, talk to you soon. Bye bye.

FARNAN: Okay, bye.

(End of April 24, 2020 interview)

Interview of Ash Farnan
SESSION 2 (4/27/2020)

[00:00:14]

YIU: Can you hear me okay?

FARNAN: Yes, I think so.

YIU: Perfect. How are you doing? It's Monday—it must be your busy day. You said you have a long day Monday?

FARNAN: Tuesday, Thursday are my class days, so those tend to be my longer days. Monday is one of my internship days. So, it was pretty slow over there, actually.

[00:00:40]

YIU: I'm glad to hear that.

FARNAN: Yes, how about you? How are you doing?

YIU: I'm doing great. Thank you for asking. And today's weather and this weekend has just been wonderful. Yes, we're loving it.

FARNAN: Yes, it's been really nice.

YIU: Yes. So, last time when we were talking, we talked about you living in Portland at the time and working for an NGO. And this time I wanted to talk more about how was your life navigating higher education with your symptoms?

FARNAN: I would say it's indirectly impactful, I suppose. I guess I can start by saying that I'm so much better than I was even a year ago—both physically and mentally—so even though I'm still pretty sensitive, I think I have a different relationship to it than I used to. So, I think that makes it much less difficult to move through the world. But in tangible terms, I would say that just in general that I'm still pretty sensitive to buildings. So, it does kind of impact—it's a thing in my life. So, it's difficult for me to be in any building for an extended period of time, which was fine enough when I was in school. I wouldn't say that the Luskin building was one hundred percent okay, but I would do enough moving between buildings, between classes, that it wasn't like it was a sitting in one place for a long time.

YIU: Right.

FARNAN: My internship building definitely had a severe mold problem. And there were a lot of stat-—yes, I won't go into the details of it. I think it was a problem that was affecting other people that wasn't being attended to appropriately, but I wasn't really listened to when I raised the concern. Yes, and then in terms of my home space, yes—I still sleep outside. I just have to be

aware of the number of hours, consecutive hours that I'm spending inside at any given point in time.
YIU: I see. So, you mentioned that the internship building has some mold issues. What do you do to navigate it? Have you ever raised it?

[00:04:09]

FARNAN: I did raise it. Yes. I noticed it was a problem. I noticed it from the beginning. And then over winter break, apparently there was this realization—they have this special flooring there, it's a Senior Care Center. So, I mean, it's particularly problematic because ninety-eight percent, I would say of the clients there have some sort of dementia and mold is a neurotoxin, so it's not very good. Yes, so they identified that something about the flooring—there was water that was accumulating under the flooring and it was starting to pucker and bubble. That's when they noticed it and then over winter break, I guess they had the people come in and redo parts of the floor. But I don't think that they were in any way aware of mold or doing it in a mold literate way. So, my understanding is that they just ripped the floor out and put it back in. I came back after winter break, and it was horrifically noticeable. There were people in my organization that were just being sick all the time—people with chronic sinus infections, people who got headaches all the time—I raised it to my supervisor. She was like, "Oh, okay, that's maybe something that we should look into. I'll talk to the executive director about it," but I don't think that she really took it that seriously.

YIU: So, that's how far it's gone—is the recognition that you've reported to them.

FARNAN: Yes, yes. I think I still also have some mistrust in myself of not taking myself fully seriously. So, there's a part of me that doesn't fully trust myself, which is, I think affects how much I push it. So, but that's right. Yes, that's fundamentally as far as it went.

YIU: Can you tell me more about why you don't trust yourself when advocating for your needs?

FARNAN: I think because it sounds so silly. I think the me before this all happened would not––I didn't, I mean, more like I guess I would have known intuitively that it wasn't great to live in a place that has mold. But I don't think that I would have had the level of awareness that I have now of what a problem it can be so I think I see that other people don't take it as seriously similarly, and I don't know. Sometimes I joke it's like The Boy Who Cried Mold like people don't think like yes—I think there's still a part of me that wonders if I'm just picking up on something that's not really there or if I'm blowing it out of proportion. So, I have an insecurity about it and that makes me not inclined to push my interpretation onto other people.

YIU: Yes, that completely makes sense. Do you think that previous experiences and/or structural oppressions such as, let's say sexism or homophobia would affect the ways in which you readjust how you tell and how you advocate for yourself?

FARNAN: That would readjust how I—

YIU: Yes, because you were saying that because of—you don't want to feel silly even though you know that your body is telling you your truth, which makes it so difficult to advocate for yourself. Do you think that some of the barrier has to do with how your previous story has been received and/or structural things such as sexism, classism and direct access to health care? [00:08:57]

FARNAN: I think I could probably pretty safely point to particularly gender related conditioning around my assumption that what I have to say isn't as valid or a wariness of claiming space or taking up space or demanding something, or even believing myself that my experience is valid. I would say, yes, I would definitely connect that to—I mean, probably I would connect it most directly to gender.

YIU: Yes, could you tell us more about what some of those experiences of gender as something that structured your experience?

FARNAN: I think it's interesting that I'm pausing right now because I've devoted my entire adult life to—like I was a gender studies undergrad. This is my lens on the world. And so, the fact that I don't have a ready answer to this question makes me feel—it's just funny.

YIU: I think it's because gender is so complex, right?

FARNAN: Yes, it's true. Yes, that's true.

YIU: I think you should take as long as you need to come to an answer because I don't think that you need to have readily available answers at all.

FARNAN: Thank you. You're very affirming. I guess just thinking about my own family background and gender conditioning, I come from a very conventionally binary family. The women in my family, especially on my mom's side of the family, which is the side that I would say was most present in my upbringing, are extremely disempowered. There's a lot of misogyny and my family I would say, subtle and in some cases more explicit. I think I just I really grew up surrounded by women who hated themselves, to put it bluntly, and who weren't quiet about saying that out loud around a bunch of young girls. I think there was just this idea that—this feeling of just shame, which continues to this day of shame around what right do I have to exist or to take up space or to claim my truth or to assert my truth. I would say (that) was the message that was communicated. But I mean, I would think that there's—in terms of my life experiences in the world, definitely my class and class privilege and racial privilege clearly intersect with my gender experience. But I didn't give you very specific examples. Would that—and that I feel like that's kind of what you are asking for, right?

[00:13:09]

YIU: Yes, I think that's such a critical reflection of how different things intersect to create your unique experience. You were mentioning last time that you were at—and I messed it up, I said Portland earlier, but it was Seattle that you moved from—that from Seattle, you moved back with your father?

FARNAN: That's right. Yes.

YIU: And so, you are still staying there now, but you're still sleeping outside?

FARNAN: I'm not right—I have a place in LA (Los Angeles, California). But I kind of bounced around, even though I'm paying rent in LA because the LA house I feel pretty sick in if I spend more than five hours at a time inside the house. The working from home situation makes that difficult. So, for a while I had been spending some time at my dad's house because that place makes me feel like a little bit less,—I can stay there inside for longer periods of time at my dad's house and feel okay. But then I was starting to get worried that I could be potentially exposing him in terms of COVID. Now I've been staying for a little while at my grandparents' house. They're not here, and I'm mostly am outside while I'm here.

YIU: How would you describe some of the barriers that you experience with someone who lives with MCS in terms of housing and finding housing?

FARNAN: Yes, it rules my life. It's been the most— it's been very difficult for the last couple of years. I mean, I've given up on the hope that I will find a place that I feel well in. I think right now I'm in a stage of like, "Is it okay enough to endure?" At the point when I decided that I was going to— when I finally decided to try moving out of my dad's house, I moved into one place and then I started to feel pretty sick after a couple of weeks. It became clear it wasn't working so then I had to move out of there. So, I've had to break that lease. The other places that I've looked at, I have to ask the people if I can spend a night in the house or something which a lot of people aren't okay with, understandably.

YIU: I think just as you were mentioning that process of self-advocacy in order to find suitable housing for yourself, how does that conversation look like for you with the landlords?

FARNAN: I think part of what has maybe made it a little bit less awful than what otherwise might be is that generally when I've looked for housing I've gone through queer housing Facebook pages. So, the people who I've ended up going to seek housing, they haven't been big corporate landlords. They've been like a bunch of queers who are renting out a room in their house or something. So, they're better. So, they've been a little, like there's been less of a treating me like a—I mean, I guess I should accurately say that, in general, people have been pretty receptive to it. So, I usually just tell them that I have a lot of sensitivities and that it's helpful for me if I can spend a little bit more time in the space before I make a decision. Some people have said no, and a couple of people have said yes.

[00:18:05]

YIU: And has that been a reliable test that for you? Because it sounds like even with that, you have not been able to find suitable housing that's okay long term.

FARNAN: No, it's not really been a reliable test. Which, like, I don't know, could also be—I mean, I feel like this is also where the mind plays a role too. If I'm going into a situation where

the stakes feel that high and I'm already so geared up to like, “Am I going to feel something?” I feel like I'm setting in play probably physiological processes that are not conducive to a state of calm. And so, yes, I don't know how. Yes.

YIU: Yes, I mean, you've mentioned you have had to break several leases in both Seattle and in Los Angeles. So, I'm guessing it'd be difficult to put down people as housing references. Has that made your experience of finding housing even more difficult?

FARNAN: Yes. I mean, I think again, that's where it's been like the type of housing that I've been looking for and the type of people I've been talking to haven't really been the type who are diligent reference checkers. It might—it probably would, although I don't know—I feel like the people who I have lived with I feel I've still built connections to them in a way where it was inconvenient for them that I had to leave, but it felt like the bridge wasn't totally burned. So, I don't know. They may be able to attest to it my good character, but my inconvenience as a roommate—I don't know. So, I don't know how far that would go with—

YIU: Right. So, would you say that, it sounds like the queer community has been an important source of support for you. Do—

FARNAN: You’re right, yes.

YIU: Do you have any other forms of relationship that you've developed to help support you dealing with your illness?

FARNAN: I'm on a few of the Facebook pages, but I’m not really active in those kinds of spaces. I've tried to actually reduce the amount of attention that I paid to them because I find them very triggering. So, I'm not really an active member on those, in those communities. I have a couple of friends who I would say in general, believe me who I'm close to, who I can talk to. You're asking just people who are sources of support in general or people who like specifically with regards to the illness are—

[00:21:38]

YIU: I think I think both were valid, but more generally, how have your friends accommodated your needs of access, per se?

FARNAN: Yes. I would say of the few friends that I have, who I'm close to, most of whom live not nearby are scattered nationally and internationally. They believe me and they are—I mean, I went to stay at one friend's house and she had a backyard and she actually set up a tent for me in her backyard so that I could sleep in that. So, I think in general, they believe me and are willing to accommodate it.

YIU: You mentioned that when you were in Seattle, you were briefly seeing someone. Has your symptoms and/or your illness affected the ways in which you date?

FARNAN: I think, yes, during the period of acute illness in the two years or so after the initial exposure. I guess after that relationship—that short lived non relationship with that person kind of died—I think I just was so isolated and consumed by the experience of being ill and thinking about being ill and stressing out about housing that dating was not something that was at the forefront of my mind at the time. I haven't really tried that much to date. I do think sometimes about what it would it be like if I had a partner who wanted to live inside a house like a normal person. I don't know how to navigate that—how I will navigate that. I dated one person for a while about a year ago. They also lived up in Seattle so I would travel up there and he had an apartment that was a very new and very chemical-filled building that I struggled with, but we also spent a lot of time like camping and hiking and stuff, which was really helpful. So yes, it was a factor for sure in my state of wellness while staying in his apartment.

YIU: Yes what was it like advocating for yourself and perhaps even demanding changes in the other partner's grooming routine in your intimacy or in your intimate relationship with others?

FARNAN: I think this person luckily was already pretty environmentally conscious and not into using a lot of grooming products. So, it already wasn't that big of an issue. He did get an air purifier for the apartment and he tried inquiring with the apartment complex because he thought that there was something wrong with the HVAC (heating, ventilation, and air conditioning) filtration or the HVAC system. He was pursuing leads, but I think—so what was it like advocating for? I think I had the power in that relationship. So, it didn't—I don't know. Fundamentally, I'm not sure how deeply he believed me. I think he's very—yeas, I don't need to go into the whole conversation about it, but he took steps as if he believed me. I'm sorry, I feel like I'm giving you very non answers today.

[00:26:52]

YIU: No, not at all. I think you're giving me great answers, and it's also like not a questionnaire with pre-described categories of expected answers. So, I just wanted to get a sense of what are some of the barriers of being intimate with others while living with chemical sensitivity. So, I think that answers that for sure.

FARNAN: Yes, I think I would say that the real test hasn't come yet because I wasn't invested in that relationship emotionally. And so I think had I had an idea of like, "Oh, this is a significant relationship and we are going to need to make things work logistically and environmentally," that may have induced more conflict and panic and I assume that test is going to come, so TBD (to be determined). Yes.

YIU: Yes, and it sounds like you do maintain relationships with your friends, but do your symptoms impact it in any way?

FARNAN: I think it did before. I would say up until a year or so ago. My M.O. (modus operandi) is if I feel overwhelmed or—I disappear. I'm a withdrawal person— definitely avoidance, if you are into attachment theory. So, I've definitely had instances like, I'm—one of my best friends, Sarah, who lives in Dublin, who I would say of all the people in my life probably sees me the most clearly and loves me the most and is willing to forgive my bad

behavior. When I moved into a house—this would have been I think, March of last year, so a little over a year ago—and that was my first real foray into a place after moving out of my dad's house and after the first couple of weeks started really feeling like it wasn't working, health- wise and it was just so overwhelming for me and spiral-inducing that I just basically said to everybody in my life, including my therapist, "I just need to check out right now. I can't." And just cut off contact with everybody because I just couldn't— I was so in it. I couldn't be out of it enough to be in contact with other people. So luckily, I have friends who, for the most part, tolerate that. But yes, I would say it impacts it mostly in that way.

YIU: And do you think that similar things impact your family life as well?

FARNAN: In two of my sisters who live locally, both of their—one lives in an apartment and the other lives in a house—I don't feel well in either of their homes. So, I don't visit super often, and if I do, I don't really spend a ton of time there, especially if we're in the house a lot. But I would say in general, not so much directly because I feel like it's already not something that I talk to them a lot about. It's just not something that's super present in our relationships, I guess.

YIU: Do you—it sounds like a lot of things to keep within yourself and to not discuss it with your sister and sometimes you know that this—your description of closing in—do you maintain any relationships with other folks who experience MCS that helps you navigate that or how do you deal with those emotions?

[00:31:53]

FARNAN: There was a time where I was trying to like—actually I don't know if I was actually trying it so much as it was just happening. There was a time maybe about two years ago where I was on a dating app and I ended meeting up—I ended up happening to end up in conversation with two other people, both non-binary people—both of whom I've reached out to for this study, but neither of them responded to me, or I don't know, maybe they read it and maybe contacted you directly who both had (MCS)—but I think that I almost found it more triggering than hopeful. I think just then it was the thing that we would talk about. We would just talk about it. I mean, I didn't go out with them that many times, so it wasn't like there are that many occasions but I think it became—then it's easier to just get sucked into talking about it which can be more triggering than helpful for me. So, I would say probably the most helpful thing has honestly been that dance practice, which like—I mean, you used the phrase of like, I don't remember exactly what phrase you used, like being, I don't know—something about things being stuck inside. I think that really helped me to move things through my body in a way that's really helpful. I think my level of engagement in community or in close relationships predates the illness—or my challenges with that predate the illness—so reaching out for support is not something I'm always very inclined to do.

Are you still there?

YIU: Hello, can you hear me?

FARNAN: Oh yes, now I can hear you.

YIU: Oh, sorry, I must have hit mute. Sorry, I was asking if there were any particular achievements that you're proud of, that you'd like to share with us, whether it was advocating on behalf of yourself, your doctors or talking to your supervisor about the mold.

FARNAN: I don't know that I would choose the latter because it feels like I probably should have or should take that further than I did. I think talking to you about it right now and hearing myself say it out loud is making me realize that. But I don't know like maybe—I guess personally speaking, I would say that the learning to be more comfortable with asking for what I need or taking up space, particularly with regards to seeking housing, I would consider to be—I don't know achievement feels like a big word—but a good step in my own process. I think maybe more generally, I would say that I have now, such a more embodied awareness of the transience of health, of how it really is just luck. And like, for the most part, and what it is like—and I know that there are so many people who have it so much worse than I do. So even just my taste of what it's like to suddenly wake up and not be able to count on your body in the same way or have the same levels of energy available to use, to move through the world—I think understanding that in my body has made me a better— I'm so much more attuned to it and willing to advocate for it. And I mean, so far not in super formalized ways, but I think professionally, just when I am meeting with clients, or conferring with others about clients, I think I have an ability to see and hold space for the mental pain that comes with living with chronic illness in a way that that I might have just breezed by before. And so, I have had a number of meetings with clients where I feel like we've been able to really go into that in a way where it felt like it was—like I just know for me when it has been so helpful when some—like when my therapist, for example, has really made space for the discussion of what it is like to just have a body that's not working properly. I feel like I'm not articulating this well. I think also just advocating and conversations for people who expect a certain level of performance or productivity or might judge somebody for not being as active or productive as they would be as if it were their choice. So, I think I'm better able to disrupt those narratives in both personal and professional settings because I felt it very intimately. Sorry, that is not an achievement.

[00:39:25]

YIU: No, that's great because it actually leads me to my next question. Yes, because they think it is—I'm sure your experience of how you have come to cope and learn about your body has changed your awareness of not only how chemicals affects yourself, but also affects others. So, I wanted to ask you about, how have your symptoms made you more aware of how chemicals affect we know—you said not just our living world, but in terms of our body because the last time you also talked about the environment.

FARNAN: Yes. I think I have a much deeper awareness of—we are paying the price. We are going to pay the price. We can't get away from it. We can't keep filling the planet with toxins and think that we are outside of the web that is impacted by that. We think that we can separate ourselves from that with our technology and our brains. But I don't know—I mean, I know that's what (Bessel) van der Kolk is talking about trauma when he says this, but the body keeps this score like the—we are bodies. And so I think to me, now it feels less intellectual, like why one

would choose the products that one chooses, or why it matters what kinds of products we are consuming or what kinds of processes we're using to produce things.

YIU: Why do you think that now we're thinking less about those processes of production and its impact?

FARNAN: You mean like in the modern world—is that?

YIU: Yes.

FARNAN: I feel that we are disconnected from our bodies. At least in the West, in particular, and I would say I think this is—I feel like it is patriarchy and capitalism. We think that we're less inn our bodies and we're more afraid of our bodies. I feel like—okay, going back to the question why why are we—yes, our bodies and the earth. I feel like this all sounds so cliché, but so many of us are so many steps removed from how we fit in or where we fit in to the natural world. We no longer see ourselves as embedded in it. We're separate from it.

[00:43:29]

YIU: Yes, I think a part of what you were saying in terms of capitalism and how it works in tandem with other structures in producing these chemicals where we're no longer choosing intentionally, does affect how our environment works is what you were framing. Which makes me think about, what are some of the steps that you believe could change that relationship?

FARNAN: It is hard to imagine how we can—this mess that we've gotten ourselves into. But let me just take a second to think about it. I feel like there are really macro answers and then there are really, really, really micro answers to that question, but—

YIU: I'd love a little bit of both if you don't mind. That's actually my last question for the day.

FARNAN: I think for a philosophical framework or something I feel like the level at which our society is so structured around distraction, how distracted and disembodied everybody is, and increasingly isolated—I think that those are all parts of it. I know I keep coming back to this theme, but it really, through my own personal experience, feels to me the more that we are feeling what is happening in our bodies and really feeling the impact of things on our bodies, the harder it becomes to not connect our experience to what's going on around us in the world and in the planet and in other people. So I feel like there's—I think about my time and I spent some time working in India and then also studied abroad in Africa. I feel like, especially in India, my relationship to my body changed so much and I feel like it has so much to do—I don't want to—I'm wary of making any kind of generalizations or anything like that, but it felt like there was a more of a sense there that less—and part of it might just have to do with the fact that there are so many people to cram together all the time that it's like you are with other humans. It's unavoidable—and I'm not articulating this well—and less of a sense of shame around being in a body and having a body. I mean, just the way that people would talk to each other about their bowel movements. It was a normal topic of conversation. It was just something you talked about because you were a human with a body and you have bowel movements and so does everybody

else—things that would normally be very shame-laced here. People would take their shoes off in the office. There was just—there was something, or a lot, that was different.

And I'm going off topic—I would say macro, regulatory policies that make decisions or structure decisions for us that maybe shouldn't be left to the individual choice level around what kinds of chemicals or pesticides or things can be used or what can be dumped into oceans or what can be fracked or all of those things that have a longer term vision in mind and not just short term profit. And then, giving children more of an opportunity to be in nature. I would say really indoctrinating kids from an early age into their place in the ecosystem, as corny as that sounds. I look at my niece, who just lives in the suburbs and pretty much leaves the house only to go to Target with her mom and thinks that all insects are monsters and is terrified of them and is just very afraid of the natural world. I just think that that's setting future generations up for further dissociation from it, which then enabled us to harm it without awareness.

[00:50:44]

YIU: Thank you so much. I think it was beautiful that you talked about how there's so many taboos within the West that you have not experienced at your time offshore and how that connected to different parts of our relationship with chemicals and tastes. Before we end today, I just wanted to ask you if there's anything I haven't asked you that you would like to have for the record.

FARNAN: No, I don't think—there's nothing that I can think of right now. Thank you though for asking that.

YIU: And if you ever think of anything, please let me know and I'm always happy to do another follow-up interview or chat with you about whatever it is that you're thinking about. Thank you so much for the generosity of your time and for telling your story with such grace and clarity. How do you feel now after our interview?

FARNAN: I feel like the generosity of your listening and the questions that you asked and the space that you gave me to—I always think about how the quality of the listener impacts so much about what the speaker is able to even conceptualize and articulate. And I feel like I've been able to—I think it was a really—I've been able to articulate things or put things together that I hadn't had an opportunity to do before. I think it's given me like—I've maybe had thoughts about different things like this that have been scattered or disjointed, but I feel like it allowed me to see how I've made meaning out of this experience in a more cohesive way. And that has been a gift.

YIU: Thank you so much.

FARNAN: I'm really grateful.

(End of April 27, 2020 interview)