

Interview of Nadine Waters

Session 1 (7/28/2020)

Timed Log

[00:00:00] Born in upstate New York. Identifies as a Caucasian female from a middle-class background. Stay-at-home mother who occasionally did part-time office work and father worked in machine shop. Infrequently visited dad's workplace but recalls an oily scent.

[00:04:28] Developed sensitivity around three years ago. Before then, health was fine. Would get headaches, but no breathing issues or heightened sense of smell. Developed severe panic disorder and PTSD at fifteen or sixteen

[00:05:04] Grew up with a dog. Mother cleaned with lemon scented products and couldn't tolerate floral scented cleaning products. Lived on outskirts of town near state border in a quiet neighborhood.

[00:06:07] Started developing sensitivities after exposure to deer and rabbit repellent spray used by a female coworker to stop animals from eating plants. Suffered severe asthma attack three hours after exposure and went to urgent care. First asthma attack at twenty-nine. Was unaware she had asthma before. Had been working as a home health aide at the time and was participating in Master Gardener program at time of exposure. After first exposure, stopped working with Master Gardener program on allergist's recommendation.

[00:09:54] Mother first had thought she was having a panic attack, but doctors were able to confirm throat was inflamed. Found the urgent care doctors kind. Thought she would be better after healing in a week but started to notice increased sensitivity to scents. Started to notice scents in therapist's office. Thought it was a normal part of recovery. Believed that this was a one-time event and only would need to avoid garden sprays.

[00:11:56] Over the past four years, she developed increasing sensitivities and very acute sense of smell. Has vocal cord attacks and cannot speak. Family has had to remove chemical cleaning products from life. Cannot spend time with sister and family anymore due to scented laundry products. Cannot go for walks in the neighborhood due to scented products. Boyfriend stopped using scented aftershave. Cannot be around smoke like campfires or barbecues.

[00:13:53] Allergist tested and concluded it was chemically induced. Treatment is avoidance and emergency inhaler. Avoidance is difficult. Started house hunting recently but finding fragrance-free house and neighborhood that does not have chimneys, for example, is difficult. Concerned about potential neighbors' pesticide and laundry use. Currently lives with parents.

[00:16:39] Had to stop seeing therapist of a decade and a half for PTSD because therapist used scented products. Therapist's husband was a psychiatrist in the same building and recommended interviewee have family physician write prescription for antidepressants. No accommodations were made. Therapist insisted products were necessary to control germs.

[00:18:34] Pulmonologist diagnosed asthma, vocal cord dysfunction, and severe chemical intolerance. Was not surprised by diagnosis, and feels it is incomplete. Identifies as someone with a disability. Believes it is multiple chemical sensitivity (MCS). Boyfriend found another woman to consult with about mold toxicity was building a safe house.

[00:20:24] Difficult to avoid products, people, and places. For house hunting, boyfriend pre-screens house for scented products. Previously only considered if house was smoke-free, but now list of things to avoid is overwhelming.

[00:21:35] Financial burden because she had to give up being a home health aide. Some clients were fragrance-free, but the vast majority used scented candles, reed diffusers, or detergents. One client did try to remove scented candles, but some oil-based scent residue stayed in the carpet and furnishings. Manages financially through disability and boyfriend's help.

[00:23:38] Not on disability for chemical issues. Was a smooth process to get disability due to long history of and amount of documentation for PTSD but believes it would have been difficult to get disability due to chemical exposure. Had a bad experience with primary care doctor who did not believe her and dismissed her concerns. Switched to different doctor who cleans with hydrogen peroxide. Has difficulty with access to medical care due to sensitivity. Went to hospital for blood draw and had a reaction. Reluctant to go anywhere, which is increased due to COVID-19.

[00:26:12] Would like to see all medical facilities, including veterinary facilities, legally required to be fragrance-free so people with asthma, migraines, or other issues can access them. Prefers hydrogen peroxide as a cleaning alternative. All healthcare providers should not use scented laundry products or perfume to better help patients access care. The problem is either people are not aware or don't believe it.

[00:28:10] Does not fully explain medical problems to primary care doctor. More comfortable talking to pulmonologist who has some degree of intolerance herself.

[00:29:01] Aside from avoidance, does not use other strategies. Will leave immediately if there is a bad response.

[00:29:37] Has been dating boyfriend for seven years and condition started during dating experience. Boyfriend did not react well at first and disbelieved her. Thought she was being controlling and just disliked scents rather than was getting sick. Boyfriend was angry. Became depressed and hopeless because no one was listening. Family also dismissive at first. After boyfriend learned about other woman with mold illness in the same year, he believed her and started being supportive. Was relieving to have boyfriend believe her and made accommodations. Does wear scented products at work but does not bring them into the house or will shower and change if exposed.

[00:34:12] After being treated for PTSD, panic disorder, and agoraphobia having sensitivities is especially difficult to cope with emotionally. Parents have been more difficult than boyfriend. When mother was around the same age, she had the same problem and is still sensitive to

perfume. Mother believes it was from carbon monoxide exposure in her twenties. Believes there may be a genetic component.

[00:36:25] On an MCS Facebook group and has done a lot of reading. Talked to an architect and the architect's doctor who both had MCS and took measures to recover, including having special houses built with non-toxic materials. Recovery took years. Does not have the same financial resources. Doctors who treat MCS do not usually accept insurance and there is also no guarantee treatment will be effective. Would like to see a doctor for detoxing but it is too expensive. Closest doctor would be three hours away so other barriers arise, including transportation and finding a fragrance-free hotel nearby.

[00:40:42] MCS groups are helpful. Architect wrote a book that discusses different housing materials that has also been helpful. Finds it surprising how much there is to learn about toxic materials even though she has a bachelor's degree.

[00:42:17] Chemical companies are wealthy and pay for silence. Companies do not want this information to come out because it would affect profits and they do not care how it affects others. Reaffirming to find MCS Facebook group but also sad to find out how many people are going through the same problem without it being addressed. Shocked, disappointed, and surprised at society for allowing this.

[00:45:20] Discusses sensitivities with MCS group and also two of her friends. She has not told others, including her extended family. People question the reality because she looks the same as before and has an anxiety disorder. People are emotionally attached to products and don't want to change them.

[00:47:08] To cope she sews, keeps a journal, quilts, pebble art (uses glue with low odor), and baking. Cooking odors can be difficult sometimes, including the self-cleaning oven odors. Will open windows, close kitchen door, and leave the room while items are baking. Things don't smell the same, such as barbecues where she can smell the lighter fluid.

[00:49:14] Has not participated in any advocacy efforts because she has not heard of anything. Would want to participate but has been focused on dealing with immediate family and doctors. Has changed veterinary office of fifteen years. Complained to veterinarian, but no changes were made. COVID-19 disinfecting protocols have made it harder to leave the house to go places, such as the grocery store or hair salon.

[00:52:21] Never thought this could happen. Had not heard of anyone with it or known mother had it too. Mother's sensitivity has lessened over time, but hers has gotten worse over time. Sensitivity has made her more depressed and bored. Afraid to go places. Wants to live without fragrances dominating life.

[00:54:46] Does not feel race or gender has impacted experience of illness. The biggest impact is longstanding anxiety disorder. People and healthcare providers do not want to believe sensitivity is real, so they don't have to make changes. Feels insulted when she is discredited based on prior mental health history. Knows of some people without prior mental health issues who are being diagnosed with anxiety due to sensitivities.

[00:57:51] Legislation is needed to combat the chemical companies and raise public awareness. For health history, also has severe GERD. May be some connection between food intolerances. Has had to take medication to control stomach acid. Gastrointestinal tract also affected by chemical exposure. Doctors have not been making these connections, but she has been piecing it together through her own research

[1:01:28] Thankful that these oral histories are being recorded. New York law passed recently for nail salons to have a new filtration system. Nail salons were one of the first places she could not go to and she initially thought she was having a panic attack.

[01:05:05] End of July 28, 2020 interview.