Interview with Rosie Dano

SESSION 1 (2/18/2020)

Timed Log

[00:00:00] Introduction: Born in New York, lived there for forty years. Moved to Toronto for twenty-two years and then to Charlotte, North Carolina for two. Currently living in Nelson, British Columbia with her son.

[00:01:19] Originally an only child; however, father died when she was three and mother remarried twice. She has a brother and sister from mother's second marriage (which ended in divorce), and three stepsiblings from mother's third marriage. Suddenly becoming the middle child, it was very hectic and had to go to family therapy to get used to the blended family.

[00:03:48] Only person in her family to experience chemical sensitivities, having four genetic markers for Multiple Chemical Sensitivity (MCS) through a genetic test; two from each of her parents. Relief at knowing that the illness was not her fault.

[00:07:12] Father was a news reporter (a typesetter), print shop owner, and Olympic-level swimmer; mother was a homemaker and was a smoker. Her first stepfather owned a paint and hardware store, smoked cigars. Second stepfather was a pharmacist, had a drug store. Did not really move much throughout her life, but moved around as an adult. Not as close to her siblings due to MCS. MCS has caused her life to change radically.

[00:10:02] As a child, had a complete scratch test to determine her allergies. Results found that she was allergic to house dust and chocolate. Did not receive any explanation from her mother as to why she received this test and still does not know to this day. Sensitivity to paint rollers. Remembers being foggy every once in a while but does not know the exact cause—could have been due to either stress or chemicals. Does not remember why fogginess started but began when her father died; went from a vivacious, outgoing child to being withdrawn.

[00:14:10] Her mother cleaned excessively, used a lot of cleaning products, such as Airwick, Lysol, Pine-Sol; also used Raid for ant infestations. Mother washed Dano's brothers' clothes in Blue Cheer.

[00:15:47] Remembers mosquito spraying at summer home in Lake Mohegan when she was married and had a son. Told to stay indoors but was still exposed. Went into anaphylactic shock, combination of being stung by bee and being exposed to malathion insect spray.

[00:17:33] Familial relationship regarding MCS: Father believed she had a physical illness but did not completely understand her MCS, while siblings remain skeptical. Asked family members for help but they felt she didn't work hard enough in life and don't believe she is actually sick. Great strain on familial relationships and friendships. Relationships dropped by the wayside, could not work or do the activities she previously could, had difficulty adjusting to this new way of life.

[00:21:00] In high school, she often passed out, but others chalked it up to her being anemic or wearing too tight of a belt. Following her marriage, she bought furniture, remodeled the house, and as a result was overwhelmed with symptoms. Devastating but she got better—but each time she had an “incident,” she never fully recovered. Had her second child, was remodeling her home again and the symptoms reappeared. Her son’s pediatrician doubted her symptoms but after attending a medical convention, called her back to confirm she was actually ill after hearing a story about a NY Supreme Court judge with a similar condition. He apologized to her and gave her advice on managing her symptoms; she was relieved that someone had finally believed her.

[00:27:00] Went to work for her friend at a hair salon—her sensitivity was severely heightened, and she passed out. Stopped working as a result and moved to Toronto. Prior to that, she had given haircuts on her patio and did freelance art in Toronto. Following her divorce, she worked in retail at Danier for thirteen years, worked her way up to supervisor to get insurance coverage for her and her kids.

[00:31:11] Symptoms reappearing and becoming more severe. She usually cooked big dinners on Sundays for her family and friends and discovered one night she could no longer taste parmesan; from there, everything went downhill. Sense of taste and smell became heightened, became extremely sensitive, could no longer sleep in her bed, eat well, or bathe with soaps that once worked for her. Went to her family doctor, suggested she go to a psychiatrist at St. Michael’s Hospital in Toronto. Met with Dr. John Molot, who diagnosed her with multiple chemical sensitivities. Began seeing an allergist who suggested she expose herself to more chemicals—he was eventually fired and had his license taken away.

[00:34:56] Overall, her experience with doctors have been bad. Back when she first struggled with sensitivities, no one listened to her or knew what MCS was. Believes pharmaceutical companies want us to be sick to sell medication; frustrated with their refusal to recognize that chemicals can make us sick.

[00:36:44] All her savings are gone due to her MCS struggles. Could not pay rent but received no help from anyone. Called the ADA three times, talked to a person who kept on telling her that she will end up homeless because there is no legislation to protect people with MCS. Eventually moved in with her son in Canada, though all of her items had to be put in storage.

[00:38:56] Her husband was not a nice person; he completely ignored her MCS. Her son is also not an advocate for her MCS.

[00:40:08] Prior to high school, had no other symptoms that she could remember. Only remember passing out in high school. When she worked in the department store, she could not be in the electronics department—felt disoriented and as if she had vertigo. Fairs in Toronto during the summer—had huge speakers and when she approached, she felt disoriented, fell. In high school, had art and also had to travel by bus, subway to reach school. In earlier years, did not have as much exposure.

[00:42:53] She is always doing art every day, regardless of whether or not it was her job. Used different mediums to work with art. After high school, she attended Fashion Institute, involved in Art Students League and attended other art classes at other schools.

[00:44:10] Her art is more focused on life drawing, the human form. Has not really involved MCS in her artwork; more so in her writing. Her art is much more spiritual. However, does write on some MCS blogs, giving advice and guidance.

[00:46:10] After 1997, her life came to a halt. Could not go outside or even stay inside, nothing was right. However, discovered The Big Carrot, an organic food store, and found a leaflet that related to her symptoms. Also found a local naturopath that was willing to learn and began working with her and Dr. Sherry Rogers who deals with environmental illnesses and MCS. Switched her naturopath to Dr. Scott (surname inaudible), who have both helped her.

[00:49:01] Both conducted a procedure, NADT, an allergy elimination technique. Learned what she was allergic to. Both doctors have incredibly changed her life. Right now, she's definitely improved, contributed by the environment she is living in now: in the mountains, in the middle of nowhere. Living with her second son.

[00:51:00] Naturopathy has definitely helped her better than other traditional medicine because they look at the body holistically. They also know about MCS—willing to recommend anyone who is having trouble.

[00:51:40] Having to be a big advocate for the MCS community because there's no one else who would support her. Writing letters to Congress people, senators, newspaper. The newspaper was not as helpful because of an earlier article on MCS that drew a lot of controversy. Petitioned help to many people, even celebrities who refused to participate as it could have jeopardized their job.

[00:53:54] Writing for MCS blogs and different groups on Facebook. She writes to seek advice, provide advice, receive help on products and information. People have been responsive on the group sites but very little help received. Not a lot of help and accommodations from the community.

[00:56:10] This illness effects individuals in very different ways. Her son understands most of her condition but not entirely, and she has accepted it.

[00:57:40] Currently not living in her usual environment; recalled living in Charlotte, North Carolina. Had her own apartment, lived in a four-plex. No insulation, which meant she could still smell her neighbor's laundry and also had to do her own laundry at different times. Had special transportation, a bus, to take her to Whole Foods or wherever she had to go. Worked hard for five years to get her life back on track, doing everything she could to prevent harm. Began going out more, going to museums, eating lunch with friends—having a life. She could also do sketches, painting.

[01:02:06] Here in Canada, it is a different story. Lives in the mountains, have to walk or take a cab to go places. It is not a city, it is a rural mountain town. Healthier and is trying to do whatever she can to recuperate herself.

[01:02:22] Learning to let go of people who are not good for her. Her friends have emotionally stuck by her, a cousin who has supported her and a sister-in-law. Her son also is supportive, still opening up his door to her. Her older son is an entirely different story. Another friend in Charlotte who has stuck by her. In total, five people.

[01:03:59] In the town she is living in, people are more understanding to this type of illness. However, with people who do not understand, it is much easier to say that she has an allergy. However, she is not afraid to voice her opinions from experience.

[01:05:35] Collecting these oral history interviews who have MCS to create an oral history archive.

[01:06:25] She cannot wear clothing more than once before washing. This is because of her skin and other dust that collects. Her hair, she has to wash several times due to her oily scalp. She has to wash her clothes right after she buys it and cannot have it exposed. Dr. Rodgers had a similar experience—went to China, overtaken by formaldehyde and experienced fogginess. Had to wrap her bed in aluminum foil which she suggested to Dano who uses it to this day. Aluminum is used to prevent the off-gassing from products. Cannot use anything over-the-counter, which is where most of her money goes.

[01:10:20] Every hour, every second living with MCS is an ordeal. Can hardly be spontaneous, have to always plan out her day. Her friend had invited her to see a movie, took a "sniff test" but she could not go because the theater is still relatively new, still a lot of off-gassing from the walls and paints. Nothing is taken for granted—it's a full-time job living with MCS.

[01:12:40] However, once there is a routine, you can still get used to it. Books help her—she has received tremendous help from various bookstores such as Barnes & Noble and independent bookstores in Charlotte. You learn to manage your illness, learning a lot—medically, emotionally.

[01:14:15] Her examples are illuminating to understand how hard it can be to live with MCS. Never really know what to expect when venturing outside. Troubles with going to the mall, different restaurants, grocery stores who uses different chemicals. Benefit of having friends and individuals who understand and look out for you.

[01:17:09] MCS has changed everything about your life but not who you are. She still is trying to remain optimistic, trying to enjoy her life and love. Some days are harder than others, she still cries and gets emotional. However, she always rides it through because she knows where it's coming from, her symptoms, how her illness works.

[01:18:45] Gave up sugar because her first naturopathic doctor said that it was not helping her cause. Also gave up coffee and cream. However, when she moved here, she allowed herself a cup of espresso—able to tolerate it. She gave up her alcohol, her false eyelashes—but has decided not to give up her coffee and chocolate, not letting MCS take that away from her.

[01:20:52] Found a community of MCS individuals online, in two or three groups. Even where she is living now, has found great support in shopkeepers and neighbors as they are aware of MCS.

[01:22:09] In 1997, right before her life changed, her feet were burning badly. No doctor could ever find a reason for that. Once, when she lived in Toronto, she was taking the subway station and completely forgot who she was. Luckily, met one of her son's friends who helped her walk her to the platform.

[01:25:01] Another time, she could not walk out of the door of her apartment, as if an invisible force field was stopping her, could not breathe. Something she never experienced before—because her neighbor's lawn had just been sprayed with pesticides. Had to go back upstairs, wash her face, called in sick.

[01:26:27] Amazed at how her senses are heightened. Seeing particles in the air. If she had told anyone else, they would think she is illogical. It's an incredible experience, being able to see and experience what is unseen.

[01:28:19] Explanation of transcribing oral history interviews, copyright agreement. Asked interviewer on anything that she needs to be advised on. Discussing about the terms of the copyright agreement.

[01:31:29] She cannot use anything over-the-counter. Dr. Rodgers suggested a detox, prescribed certain combination of supplements. These supplements work if proper precautions are taken; however, this was not done with Dano. As a result, she broke out in hives, her body was burning. Her body was trying to get rid of the toxins but her pathways were closed; hives were the only escape. Downed orange juice and Claritin, subsided a week later. However, the supplements did help relieve her symptoms. Probably would not have struggled as much with MCS if her pathways were otherwise open.

[01:35:49] Conclusion: always be willing to advocate for yourself and learn about yourself and your symptoms.

Interview with Rosie Dano

SESSION 2 (2/27/2020)

Timed Log

[00:00:00] In the beginning of her illness, there were not many people to talk to. However, connecting with online sites, online forums, more people are becoming more well-versed with it because more people have Multiple Chemical Sensitivity (MCS). People trying to figure out what is wrong with them. But she also has to learn to take a step back because she is so empathetic; health concerns of others can also take a toll on her. Now, she is more open to giving advice to whoever needs it, regardless of who listens.

[00:03:55] She belongs to MCS sites and groups. Many people are giving advice, based on their own experiences and background in the sciences. Many people have different opinions and approaches but she does not care, just there to give advice.

[00:06:08] Really hard to take care of herself sometimes. Initially, she had enough money to save up and help with her family. Luckily, she had enough to live life at the bare minimum for several decades. However, has a lot of limitations—in terms of travelling, clothing, furniture, food. But, living in a four-plex and dealing with the smells of the laundry, more money was spent. Experienced a lot more loss in the past two and a half years, both financially and emotionally.

[00:10:23] Received little help, has lost everything. Most of her artwork is now in storage, molding. Currently depending on social security. Unlike with other diseases, no help available for those with MCS. MCS is experienced differently for each individual.

[00:12:47] She has exhausted all of her resources. She has lived in Canada previously but lost her status, lost her medical coverage. Has to make her own accommodations living in her son's house, experiencing a lot of stress.

[00:14:42] She makes the best with what she had. Previously, she was healthy, had a life, had work, a completely different lifestyle than where she is now. Now, she does talk to people, her sons, shopkeeper—however, she writes a lot. She can't afford to seek mental healthcare because she doesn't know what they can say and can't afford it.

[00:16:19] Most of her friends know about MCS so she is not afraid to open up about her illness. With her cousin, although she does not have MCS, she is aware and both support each other in their own illnesses.

[00:17:32] When working in retail, she is extremely cautious about the workplace she is assigned to. She was very aware of her sensitivities and tried her best to accommodate. However, when the time came when her sensitivities were heightened, she chose to not return to work. However, as a single mother, it was a lot easier, did not have to depend on anyone and did not have to listen to the criticism of others.

[00:20:46] Her own advice: be willing to give up everything and anything if you are living with MCS. In 1997, found a local naturopath on her street; could not go to homeopaths. Naturopath was not condescending but very limited knowledge regarding MCS. Received an invite for her cousin's wedding and did her best to follow her naturopath's instructions. However, still not at the point to attend her wedding—her cousin was extremely angered, severed the relationship. Disappointing because there's a lack of information and there's promises but you just have to try your best.

[00:26:00] Chose to stay single because it was the best thing for her. Not because she has any trust issues but does not want to deal with the complications with her MCS. Always having to be on alert, always needing to have a plan. Cannot have plastic in her house—only foil or glass. Particular in clothing—cotton or silk, no dyes from India due to the fragrance. No perfume or deodorant, no scent from other people who come into the house. It's a tough adjustment, having to really think about things to avoid—even with newspapers.

[00:30:39] Impact of MCS on your body, hormonal system, your DNA. Scientific research is available on the impact of MCS on your body. Hormonal makeup changes as a result of exposure to the toxic chemicals. Having her elimination pathways closed meant supplements worked against her body. Changing the physical being of your body.

[00:33:31] Having to accept changes throughout your life. Adapting, accepting, and morphing through the changes. Love herself through the challenges she has faced within these past two and a half years and being fortunate enough to have certain people to depend on.

[00:34:53] Many therapeutic solutions that can help with MCS, like infrared sauna, certain detox methods. However, it is not good to do these therapies alone because they can be dangerous. Have to understand your body composition and your body's functioning in order to properly help you. Can pay for different therapies, modalities of treatment but it can also hurt you.

[00:38:17] In her life, she has done everything—artist, go-go dancer, hairdresser to celebrities, photography model, fashion designer. Dated several influential men. But she never took advantage of her situations, always learned something from the relationship.

[00:41:52] Did a lot of soul-searching all of her life because she wanted to understand why she had to live this life, why she had rules to live by. Her father died young; her second stepfather did not like her; her third stepfather was amazing. Her favorite boyfriend was a fantastic artist, but she broke up with him—realized that it was due to not having a stable father figure and not having complete trust. In her marriage, she realized she was wasting her energy into turning her husband into someone he was not. Beginning to take responsibility for who she was as a person.

[00:47:42] Doing a lot of artwork for clubs, for the city of Toronto. Did hair and makeup for The Blue Jays. She did so much throughout her life and loved it. She is fine because she feels like she lived a complete lifetime before 1997. Excelled in her studies, dedicating her time to attend high school and college despite the difficulties. She did everything she could—danced, juggling, etc.

[00:51:45] Hopes that there will be legislation to help people living with MCS and their financial struggles. Wants to have people validate MCS. Does not mind being a canary in the coal mine because there is so much she would like to do, wants to educate, wants to speak out and that's how she heard of CSW, through another interviewee. Still has a lot to do in her lifetime.

[00:55:20] Conclusion: she is always looking for resources and grants that support those living with MCS.