

Personal stories from environmentally ill patients around the Environmental Health Center in Dallas

This is a collection of abbreviated stories from some of the patients I talked with during my visit to the Environmental Health Center (EHC-D) in Dallas, Texas in October-November 1999. As you will see, people who get these diseases are from a wide range of places and have varied stories. Some of the people with the most interesting stories did not want to be included here for a variety of reasons, both personally and legally. Had I been able to use more time on this project, I could easily have doubled the number of stories. I heard parts of many more while sitting in the sauna or other places - stories of broken families, homes that could no longer be lived in, people living in tents and more. The stories shown here are taken down as a more formal interview, where I met with the person privately. All persons have given their accept of the publication of their story.

It is my hope that these stories are read by other people with this disease, so they know they are not alone, and maybe they can show this to a doubting spouse. This disease is difficult to comprehend for those not afflicted by it. As most of us look perfectly normal, we do not have a wheelchair or a cane, there are many people who doubt the validity of this disease, and refer us on to psychologists. I am not a doctor, and can not validate the claims presented here, but only bring the stories for you to consider.

In the seven weeks I was at the clinic, I met people from four countries and a variety of professions, including a business executive, firefighter, doctors, nurses, teachers, computer people, office workers, housewives and many more. I noticed that most of the patients are eloquent and well educated, qualities that are necessary to battle their way this far through the convoluted and small-minded health system.

One thing to note, is that even though some people appear to become ill overnight, I believe it is just the last straw, that persons which such a dramatic change in their health were already so compromised that they just needed a large exposure to pass the final threshold.

One of the patients suggested I asked each person what they miss the most, which this disease has taken away from them. That is a very emotional question, I asked at the end of the interview. It brought tears to the eyes of several patients, after they had unflinchingly told me in detail of many years of pain and disappointment.

If you would like to see more testimonials, I can highly recommend the book "The Dispossessed" by Rhonda Zwillinger, which brings a photographic portrait of fifty people with Environmental Illness. I met one of the people in the book while visiting the Seagoville community outside Dallas; he is not included here.

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Judy D. is a 51-year old woman from Michigan. She had the carpets in her house cleaned by a company on March 25, 1999. She had never had any breathing problems before, until she entered the living room to pay the company that had just cleaned her carpets. She noticed a strong odor, that gave her problems breathing, so she spent the night in her basement. The next day she still got sick in the living room, and had to move to a hotel. Her skin started turning yellow and she gradually got worse. Soon she could not go to her church or enter a store, due to the fumes there. When she arrived at Dr Rea's clinic in Dallas, her head was in a constant fog, and she had to stay two months before she felt better and could go home again, where she now will have to work on making her house a safe place to live.

A. G. was a nurse in Boston until she got sick. She was exposed to dry-cleaning fumes from her father's business throughout her life. She started getting sick in the 3rd grade, about the same time she got her first mercury amalgam filling in her teeth. She had chest pains, trouble breathing, and often passed out. In the 8th grade, she became chronically fatigued, and had a migraine headache that lasted three years at the age of 18. She struggled through school and college through sheer willpower, which also enabled her to raise four children. In May of 1999, she contracted severe Reynolds disease and systemic scleroderma, an autoimmune disease that slowly destroys the body organs and hardens the skin. She overnight got blisters on her hands and her fingers kept changing color between white, black and normal pink. When she came to Dallas, her fingers were black and she

was facing the threat of losing her fingers through amputation. After six weeks of extensive treatment, she returned home to get all of her many mercury fillings replaced and then a year of chelation therapy to get the mercury out of her body. A blood test showed the level of mercury in her blood to be extremely high. She will also need to modify the family house, to make it safer to live in.

Howard G. is a 41 year-old diesel mechanic from British Columbia, Canada, who has worked as a mechanic for 21 years. His shop moved to a new facility six years ago, which had no exhaust system; despite they worked on diesel trucks. They washed the rolling equipment with the same water over and over again, to avoid dumping it into the sewer. The water obviously became very polluted, and as they used a steam cleaner to wash the vehicles, it was sprayed into the air they breathed. There was also a machine that washed engine parts, which was vented into the shop, instead of to the outside as intended. After working there for two years, he developed a constant cough that continued to get worse. The doctor first thought it was a cold, then an x-ray showed two tumors in the bronchial tubes and concluded it was sarcoidosis (unknown disease with unknown cause!). They loaded him up with steroids, that did shrink the tumors, but then he got extreme muscle ache and stiffness, which prevented him from sleeping. He went to many doctors, while continuing to work. His wife had to drive him to work every day. He finally heard about the EHC-D and came down here, doing sauna treatment and taking vitamins and minerals intravenously. Already after three days, a lot of the body pain subsided, and after a week, he slept for six hours for the first time in years. His wish is to be able to sleep eight hours a night.

Delia L is a 35-year old woman from Texas, who does reservations for a major airline. She was a sick child and started developing various problems, such as heart murmurs, bladder infections and sinus problems. At age 19, she started working as a staff member at the EHC-D. She started feeling better, simply from working in the cleaner environment in the clinic, where there are no carpets and people do not use fragrances and other chemicals. She became a patient herself, and the tests showed she was allergic to almost all foods. After a year of treatment with shots and food rotation, she tested negative to most foods and felt much better. In the thirteen years since, she has had a much better health, by watching what she ate, and use shots when she noticed a problem with some foods.

Wing L. is a 44 year-old executive from Hong Kong. In August 1998, she was working in her office, while they cleaned the carpets. She got dizzy, with a headache and sore throat, so she left after ten minutes and went home. Two days later, she had big hives all over her body and went to the doctor, who prescribed steroids. Knowing steroids are dangerous, she didn't take them. Instead, she drank a lot of water and did a colonic. After a few days, the hives went away. Soon after, she started to react to perfumes and moisturizers which she previously had no problems with. Perusing a bookstore, she found the book "An Alternative Approach to Allergies," she then knew what had happened to her. In March of 1999, new carpets were laid in her office. She felt really bad, but continued working, while her symptoms got worse, reacting to still more things, like books, natural gas, etc. In September 1999, she found another book, which listed doctors practicing environmental medicine, and immediately arranged to fly to the clinic in Dallas. Of the things she now can't do, she misses traveling the most.

Smokey is 14 years old and from Texas, born to a woman who was herself environmentally ill. At birth she weighed 8 1/2 pounds, and only gained one pound during her first six months. She continued to gain weight very slowly, and started to have symptoms, so the doctors thought she had cystic fibrosis. However, the tests for cystic fibrosis all turned up negative. At age 2, she weighed only 15 pounds and was taken to the EHC-D and seen by Dr Rea, who suggested taking her off milk. Within a month, she gained ten pounds, and today her food allergies are under control and she is doing well.

A.D is 37 years old and has lived in many states, but now call Texas home. Already at age 8, he developed depression and other psychological problems, coinciding with his first mercury fillings. He had no more fillings after that, and his symptoms declined over the following years. He took antibiotics for acne for seventeen years, and as a teenager he had mood swings that he now recognizes as symptoms for reactions. He did well in school, but noticed he had problems remembering things after the school lunch, which he much later figured out was caused by food allergies. At the age of 21, he ventured to Mexico, and contacted amoebic dysentery. He was very successful in college, making the Deans list. While in college, and after, he worked various jobs in poorly ventilated offices with environmental problems, such as kerosene space heaters, solvents, etc. He also lived close to an oil refinery, which he could smell every day. He started having problems sleeping and went to a doctor,

who prescribed antidepressants. These produced wild mood swings and confusion, as he became more overloaded. He moved to Colorado for his second degree, where he felt better and got off the antidepressants. He worked full time while studying, and had again sleep problems so he returned to the antidepressants, with tranquilizers added. While continuing to do well at work and study, he started to get sick a lot. After graduating, he moved to Austin and worked in an office where people smoked and used perfumes. His desk was next to the photocopier, and the ventilation was very poor. At this time his dad died, which added to the stress. He now had problems remembering, and never felt good any more. After seeing twelve doctors, several who said it was all in his head, he came to the EHC-D in 1998, and lives in the Seagoville community for environmentally ill people. He has now also contracted electromagnetic sensitivity, which makes it hard to be around electrical equipment, as the magnetic fields make him as ill as chemical fumes do. He is unable to work and has run through his inheritance and all other funds available, and is now piling up loans to get the mercury out of his teeth. The thing he misses the most, is his independence, to be able to work and support himself.

Rebecca L. of Washington State is a 55-year old lawyer, who has been sick for the last ten years. She is not sure what did it to her, but she has had hormonal treatments and three surgeries. She has also been around a lot of printed materials and molds. Due to her illness, she has not practiced law for the past ten years. Her symptoms are shortness of breath, pain in her teeth, itchy and hot skin, which also blushes, congestion, sinus pains, fatigue and depressions. She reacts to molds, traffic fumes, newspapers, fabric softeners, perfumes, freshly cut grass, terps from trees, etc Her husband does most of their shopping, as she has so much trouble being in stores and being around other people. They converted their house to be safer with tiles and hardwood on the floors, air cleaners in every room, etc. She had to stay somewhere else the first year after the remodeling, even when they used less-toxic materials.

Gail G. from Florida is 46 and worked for a company producing Styrofoam, and later a company producing envelopes. Blood tests show that she has high levels of hexane in her blood, a chemical that is used in Styrofoam. It has been a long progression of symptoms over the last ten years, with chronic headaches and sinus problems. These started when she moved into an apartment with a new carpet, and got worse when her office also got recarpeted a year later. For a long time, her job involved scanning multiple newspapers every day. She became allergic to the ink, and had trouble concentrating and remembering. She had also been drinking diet soft drinks with aspartame for a while and got concerned about the health effects so she discontinued all uses of aspartame. That helped on her symptoms, except when she was around the newspapers, which continued to make her worse. Later she would get symptoms as soon as she walked into the office in the morning, so she had to quit. She tried to be self-employed for a year, but had to give up. She is now on disability and housebound, as she can not breathe the dirty air outside or go to the store. She reacts to fragrances, traffic fumes, carpets and the ink in books and magazines, which gives her trouble breathing, burning lungs, dizziness, tiredness and migraines. Her face also swells and goes numb. Of the things she no longer can do, she misses being able to go shopping the most.

Beth D. is a 33-year old transplanted Texan, who has been diagnosed with first Epstein Barr virus infection, chronic fatigue syndrome and later chemical sensitivity. She worked in computer software sales prior to becoming disabled. She does not know why she got sick; the first time she really noticed a problem was when her husband applied a pesticide to their lawn (diazanone). She felt sick for six months after that. She was exposed to diazanone again later, when they camped for four days on a lawn that had just been pesticated. She started to notice other problem substances, such as lotions and soaps of all kinds, perfumes, fragrances, hair products and laundry chemicals. These gave her horrible headaches, constant cold and flu-like symptoms, sleeping problems, muscle pains and she were always tired. She was then diagnosed with more ailments, such as fibromyalgia. Her work performance suffered, and she was demoted. She was then off on sick leave for almost six months. The second day back at work, a coworker put on a hand lotion or such, and she could not breathe. Her windpipe closed up so much she hurt her lungs trying to breathe. Her doctor told her to go back on sick leave until the company could make the workplace safe for her. The company said they could not accommodate her, and terminated her job. Their excuse was that the doctor had not clearly stated that her illness was due to the work environment. She is now on permanent disability, which is not tied to her prior salary, so that demotion hurt doubly. As she reacts to so many peoples' toiletries, etc, she can not be around other people, nor go to public places. The biggest thing she misses is feeling good - haven't had more than a rare few hours here and there where she actually felt good during the last 10-15 years. She missed a lot because of it. More recently she misses being able to go shopping and to her friends' houses. She misses hugging people too.

Larry R. is presently living in Texas and is a 61 year-old computer programmer. He is chemically sensitive, and extremely sensitive to cigarette smoke. He has brothers and sisters are also environmentally ill, they are mostly sensitive to pesticides and cigarette smoke. He smoked himself from 1958-65 and again a little during 1981. He suspects that he was sensitive right from birth, but in 1985 he shared an office with a chain smoker. From then on, his sensitivity to cigarette smoke continued to get worse - first he could not stand to be in the same room as a smoker, then the same store as a smoker and finally even the same parking lot. He started to react to several foods, traffic fumes and even the city water. He was working as a computer programmer, but had to give it up to get away from the smokers, as he would get seriously ill when the smokers came back from their smoke break, carrying the cigarette stench on their clothes and their breath. He worked odd jobs, constantly having to avoid smokers, and finally gave up and applied for social security. He also has some retirement benefits. This is hard to live on, as everything costs twice as much when you have this disease (organic food, safe housing, etc). He moved through several states, trying to find a safe place to live, staying for periods at the house of other environmentally ill people. Meanwhile, he continued to get worse, now also having problems with the minute burning fumes generated by electrical motors in refrigerators, etc. He finally settled in an apartment in Dallas, which has been modified for use by environmentally ill. He misses being able to travel, and to be with his daughters.

Carol D. is a legal assistant in a lawyer's office in Texas. She is 55 years old and has had regular pollen allergies all her life. In 1981, she had silicon breast implants installed. By 1994, she had developed a series of health problems, such as insomnia, headaches, rashes, brain fog, dizziness, sinus pain and problems with the coordination and remembering. Until then, she had not considered her breast implants to be the cause, but she had a series of tests done, including brain scans that showed white spots on her brain. The doctor thought it was the breast implants, so she immediately got them removed. One had ruptured and the other was leaking, none of which showed up on the x-rays. She did improve after that, there were fewer head aches and less dizziness, but her insomnia was still there. When she came to the Environmental Health Center, tests showed her immune system to be very unresponsive and she had food allergies. She is able to do her busy job in a regular office environment and go most places, as long as she stays away from overly fragranced people. She does get tremendous sinus pains when traveling by airplane, so she doesn't do that much, which she misses.

Delia C. is 35 years old and has lived in Texas most of her life. She was a hairdresser for sixteen years, but had to quit as she got sick from all the toxic chemicals in hair salons. Not knowing better then, she started selling cosmetics for a well-known brand. She was only able to do that for seven months, as she had major headaches, joint pain, chronic fatigue, brain fog and dizziness on a daily basis. She has lost blocks of her long-term memories and now also has problems remembering names. She lost all her friends, as they thought she was weird when she had to change her lifestyle. They thought she just needed to 'will herself well.' Her boyfriend of four years left her too. Her family is very supportive, though, and 'cleans up' when she visits. She misses her job as a hairdresser, the clarity of her mind and the ability to go places, especially with her daughter.

Eve B. is an actor of 62, presently without a home she can live in. In 1967 she was doing a film in Jamaica, where they stayed for two months in a resort that was sprayed with DDT every night to keep the mosquitoes down. She got sick from the drinking water there, and when returning to America she continued to feel sick. She sought medical help, and the doctor told her adrenals were exhausted. About 1986, she was having problems with carpets and started to loose weight. She went to Barbados in 1989 on a plane. Before landing, the cabin was sprayed with RAID. She was sprayed directly in her face, and started coughing. The next day, she had trouble with her stomach, couldn't sleep, problems with her nerves and kept coughing. Her doctor could not figure it out, and was not helpful. Thinking it may be allergies, she moved to Phoenix, Arizona, hoping that would be a better place to live. She saw an allergist there, who thought it could be a liver problem. He tried to treat it, but it did not help on the constant coughing. He said he had had another patient with the same symptoms, and he had helped her with diflucam, a candida drug. It was a disaster, making things much worse. Some time later, she was walking down the street and was passed by a truck spraying the air for mosquitoes, and was taken to the emergency room. Her health declined once more, now with both arthritis and full-blown chemical sensitivity. She moved to Virginia where she built an environmentally safe house together with her husband, but could not live in it due to mold problems. One night she suddenly got asthmatic bronchitis and had to go to the emergency room in the small town they lived in. Interestingly, there were ten patients showing up, all with first-time asthmatic bronchitis. The nurses said they've never seen anything like it. She later talked with other people, who had

noticed a strange odor in the air that night. They rented out their home, and went down to the clinic in Dallas. Presently they are considering moving permanently to Texas. She misses being able to travel on an airplane, to go anywhere, to be free.

Dian S. of Louisiana is a 57-year old psychotherapist. At age 44, she underwent cosmetic surgery, where silicone was implanted in her face. About seven years later, she and her husband were remodeling their house, doing the painting themselves. The next day, she woke up with burning hands, feet and intense vaginal burning. The dermatologist gave her a shot of cortisone and the gynecologist prescribed a bee-sting solution. Nothing helped. She developed severe joint pains, lesions in her mouth, fatigue, brain fog, mental confusion, migraines and suicidal thoughts, none of which she had had before. When a doctor did a biopsy of the vagina, she was cauterized and started hemorrhaging. This also happened at the second attempt. She later started seeing a psychiatrist, who prescribed all types of antidepressants, which made things worse. She finally came to a prominent neurologist, who made the connection with the facial implants, which he said was actually more dangerous than breast implants. Once the implants were removed, the joint pain eased up, but she still had chronic fatigue, depression, etc. She now had five-day periods where she was bed bound due to fatigue. She went to see yet more doctors, who gave her various instructions for diets, etc. She seemed to get whatever diagnosis was in the field of the doctor she saw. She did get a lot of help from a doctor who was heavily involved in researching cancer and chronic fatigue. He prescribed sauna, exercise, supplements and organic foods. He also convinced her to finally stop working. This all helped on the fatigue and migraines, but not the other symptoms. She developed full-blown chemical sensitivity, which now makes her homebound. She can only walk outside wearing a facemask. She then decided to go see Dr Rea, whom the cancer researcher has spoken highly about. He is the 23rd doctor she sees. She has come to terms with her ruined career, which she spent so much effort building, and now just misses the freedom to go anywhere, to go to a dinner and a movie with her husband, like they used to.

Jo O. from Nebraska is 56 years old. For fourteen years she worked in a hospital office, and the last twelve years she kept the books for her husband's business. They built a new house and had to move in before it was completed. The carpenters were still working on the woodwork, painting, staining, etc. Jo developed respiratory problems, burning lungs and could not take deep breaths. She was having problems with dyes and preservatives in food, and it kept getting worse. The stomach was also bothering her now. The symptoms improved dramatically when they went away for a vacation and got immediately worse when returning to their new house. They got the county to test the air in the house for formaldehyde, it showed up as 3.0 ppm, four times higher than the highest acceptable level (there are several standards). She saw multiple doctors and even went to the famous Mayo Clinic. They all told her she was fine, it was all in her head, that she should see a psychiatrist. On January 19th, 1999 she weighed 120 pounds. When she came to Dallas, she was down to 90 pounds and is in for months of intravenous feeding round the clock, with her family taking turns caring for her. Once they return, they plan on building a new ecological house.

Lee N from Colorado is 68 years old, and had hepatitis at the age of six. This probably started all her troubles, as she the following years had problems with her goiter and thyroid, and had very early puberty. She has been in constant treatment throughout her life, adding hyperglycemia, rheumatoid arthritis and lung infections to her list of ailments. When her thyroid ceased functioning, she gained a lot of weight. While living in Pittsburgh, she was one of the founders of a support group. The first meeting was held at a local library, while someone was waxing the floors. She got very ill, with her throat starting to close on her. Since then, the same thing would happen whenever she was around newly waxed floors. She found one of the pioneers in Environmental medicine, Dr Philpott in Florida, who was able to help her, while she stayed in his ecological facility for six weeks.

She lived in various cities, as her husband switched jobs several times. She suffered sixteen gallbladder attacks, though she didn't know what it was at the time. She was afraid of going to the emergency room, as she had found out that doctors would not take her problems seriously, especially as she now knew she had an immune disorder. Eventually, it became a full-blown emergency, and they thought it was related to her allergies, as they had just painted their house. She was flown to Dallas, where a doctor at EHC-D finally diagnosed the gallbladder problem, and she was put through an emergency operation, with Dr Rea as assisting surgeon. She was not able to recover from the operation while in the hospital, as the air quality was very poor. Smelly fumes came in from the air vents, the nurses used hand crèmes, the floors had carpets, etc. She had to be moved to one of the

Environmental Health Centers condos, while she was still attached to various tubes and bags. This incident happened in 1987. She has since removed the carpets in her house, removed all dental amalgams, etc. She still has problems that are treated at the EHC-D, but has a much better quality of life.

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