

## **Case Story: Lifelong Effects of Chronic Atopic Eczema**

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I speak as a 39 year old woman who has lived with severe full-body atopic eczema, and related atopic conditions, since birth. From the entangled twine of memory, I unravel a thin thread to present an incident from my childhood, with hope that it contributes to greater understanding between doctors and patients. I applaud the open eyes and ears of those in the medical community interested in the perspectives of those with chronic illness, for we have something instructive to say about faith, care, and ethics.

As a member of an international group of eczema patients communicating via the Internet, I recently saw a posted message that I'll paraphrase here: "We've had to devise ways of keeping our son from scratching. We call him Houdini because of his ability to get his hands free. A sense of humor is certainly necessary with this condition, isn't it?"

Reading this brought shocked tears, not laughter. As a child I too was put into restraints in vain attempts to prevent me from scratching. Tragically, 30 years later, apparently little has changed for children suffering with this disease.

When the use of restraints began, I was 8 or 9 years old. The year before, I'd had an operation for removal of a benign cyst on my leg, and I'd developed a staph infection. Now I was in the hospital for an operation to remove another tumor that had appeared on my left clavicle, so close to the bone that I nearly developed osteomyelitis. My left arm was affected and in pain. It was consequently bound in a sling to prevent movement. My right arm was also incapacitated, held straight out and hooked up to an IV.

It was an awkward position to be held for 24 hours a day, and it was extremely frustrating to be left without the use of my hands, as well as being confined to bed and restricted in all physical movement. I was in that position for nearly a week.

This situation would be uncomfortable enough for any child. What must be understood, however, is the context of chronic illness in which it occurred. The use of my hands figured prominently in my eczema. I was accustomed to scratching constantly, so not being able to do so at all was a severe mental and emotional constraint.

Before entering the hospital for this operation, I had been learning to gain control of my hands. I had recently figured out a self-hypnotic pattern of repetitively touching my fingertips together, and had had some success tucking my hands under my buttocks as a calming mechanism. I was beginning to hold a handkerchief and other objects to keep my fingers occupied, as well as starting to slap, pinch, or stroke the skin comfortably without using my nails. But I was in the early stages of this control, and frequently relapsed into scratching.

Put bluntly, it was torture for me to be unable to use my hands just when I was learning to use them in positive ways rather than destructively. My other good habit, reading, was also denied me, since I couldn't hold a book or turn the pages. Lying there, unable to use the few methods I knew for handling my overwhelming feelings, I was in agony.

It was hard to believe I could feel worse than I already did. When I tried to talk about my feelings at home, my mother invariably said "Honey, thinking about it just upsets you. Think about something else. Wait till your next doctor's appointment, sweetheart. You can talk all about it with the doctor."

Unfortunately, when I tried to talk to the doctor during office visits, he would be cordial but dispassionate. When I touched upon my misery and distress, he would stand up and say "We'll talk more about this next time." Crestfallen, I would look down and nod, knowing that next time would be no different. When the going gets tough, the visit is over.

Before coming to the hospital, my mother had said, "The doctor doesn't have time to talk in the office, he's busy with all the other patients that we see in the waiting room. When you're in the hospital there'll be lots of doctors and nurses and lots of time to ask them all your questions."

But when hospital staff came in, checked the chart and "saw" the patient, they didn't see *me* at all. On a superficial level they appeared to be concerned, but I could tell they were just being polite, doing their jobs. They really didn't have time to care about the frustrated soul trapped in my little body. Their kind words were well-meaning but empty, obviously meant to pacify me while they made their escape. I heard many heave a sigh of relief outside my room. Clearly, everyone felt sorry for me, but no one was willing to engage me in conversation about my predicament. All I heard was the murmur of predictable platitudes followed by hushed sessions of unintelligible whispering in the hallway.

They couldn't say to me what I heard them say to other children: "Just take this and it will be all better" nor "It will hurt for a second but then it will be all over" nor "All you need is an operation and you'll be as good as new." As quickly as possible they wanted to move on to someone whose problem *could* be solved.

In the day, there was a certain routine to my hospital stay. My parents made regular visits, and I had meals and examinations for distraction, though I remember shaking my head and legs, the only mobile parts of my body, and sobbing agitatedly. I recall my dad saying "C'mon, stop that crying. Crying doesn't do any good. What doesn't kill you makes you stronger, you know that."

After dark, the real nightmare began. It was bad enough at home, where I rarely got a full night's sleep, fidgeting constantly and rearranging myself every few minutes. Immobile in that awkward position in the hospital, sleep was impossible.

I remember mumbling, "There must be a way out," over and over, my mind like a rat in a maze searching frantically for an exit. I tried every mental trick I knew. I promised God I would be good, urgently chanted magical incantations I'd read in a book on Merlin, and tried to recall tips from movies I'd seen about how people escaped prison and concentration camps.

At some point when a physician came in, I gathered my courage and announced "Doctor, I don't know what to do, I'm so itchy I can't stand it." I was hoping that small sentence would convey my vast unspeakable anguish and that the doctor, in his great wisdom, would be able to read between the lines. But instead he said (denying my experience), "Now we're taking care of that with the antihistamine you're getting so you shouldn't be so itchy."

"But I take the same thing at home and it doesn't do any good," I meekly objected.

"Well, you're in a different place now, and not being able to use your hands is the best thing for you. A lot of that itching is all in your mind. I think you've just gotten into a bad habit and that's what you've got to work on. OK? (said brightly, as if that solved everything). You do want to get better, don't you?" I meekly nodded. "I'm sure this medication is what you need, but you've got to give it time to work, kiddo. I'll see if I can get one of the nurses to read you a story or something."

The next time I saw my parents, my mother insisted that I probably didn't explain what I needed well enough and said "There are a lot of people here much sicker than you are. You're not going to die, honey. First they have to take care of the people who're dying. You understand that, don't you? Now you've got this nice private room, you lucky girl, look out the window and enjoy the view."

Later, when a nurse I considered "nice" came in, I spit out my entreaty as clearly as I could, to ensure that I would not be misunderstood. "Can you just sit down and talk to me about my skin?" For a moment I felt proud of myself for requesting what I really needed. But the nurse's response dashed my hopes in a way that I will never forget. "That's not my job, honey. I'm sorry but I have to make my rounds with medications and do my paperwork. What if all the patients wanted me to sit and talk? I wouldn't have time for all the important work I have to do. If I had nothing else to do, fine, but I'm busy, child. Maybe the morning nurse will have a few minutes to read you a story or something. I'll make a note on your chart about that, OK?"

But I did not bother responding. I withdrew into myself as the truth sunk in. "That's not my job, honey." Her words echoed in my ears. I had held on past emotional exhaustion, telling myself that if I just asked the right person at the right moment in the right way so that they understood, then somebody would just listen and talk to me about what was going on. But now I realized it was hopeless. It didn't matter what I said or did, everyone's attitude was one of cheerful denial. "Things aren't as bad as they seem" was the consistent message. I was supposed to feel glad that I didn't have a terminal illness, when on the contrary, I wished there was an end in sight.

I was nearly out of my mind with desperation, overwhelmed by rage, shame, and the frustration of being trapped like a wild animal. To resist responding to itching is a maddening experience when the itch is all over your body and you are unable to give yourself even a minimum of tactile sensation. I felt my mind drift out of my body, and it seemed as if I was on the ceiling looking down, knowing what "she" was feeling, yet at the same time separated from "her".

As a final insult to injury, the nurse did not answer my buzzer when I had to pee. I held it in for as long as I could before finally urinating in my bed. The sad thing is that I remember the release as gratifying. At least here was one instinct I was able to express. I remember feeling my body grow cold from the wet spot, and as I looked through the window, my mind floated out to greet the moon.

If it was only that one bad experience in the hospital, it would be a manageable trauma. But this was only the beginning of years of torment. Due to the hospital restraints, my skin *did* improve. My parents then decided to use restraints at home. Ropes, handcuffs, strait jackets, and other contraptions were used to immobilize my hands or tie me to the bed. I became obsessed with Houdini, the magician, learning his escape techniques. By self-hypnosis and willpower, I often managed to get out of whatever restraint they devised, and, feeling utterly triumphant, would tear my skin to shreds in furious revenge. The frenzied scratching that ensued was orgasmic.

To think of my "self" as my body was to feel insane. My developing ego had to separate my "self" from my body in order to survive. "It" was disgusting and doomed, not me. I wanted to destroy my body in order to save myself. I ended up in the hospital a number of times after tearing myself to shreds in a desperate effort to kill this beast who had imprisoned me inside it.

A child cannot articulate the excruciating horror of these experiences. It's hard enough as an adult. When no one even acknowledges that you're in a crazy-making situation, let alone doing anything about it, your sanity is on the line. No one acknowledged the difficulty of my position. No personnel were assigned the responsibility of determining my ability to handle the emotional stress of the situation, nor was there anyone responsible for assisting me in doing so.

The use of restraints affected every aspect of my psyche. The limited scope of this essay does not allow for details of the long-term psychological effects. It suffices to say that the mind/body split has been a devastating legacy. I believe my ordeals with eczema led to later suicide attempts, drug abuse, difficulties in school and work, multiple rape and sexual molestation incidents, voluntary sterilization at age 21, continued need to live as a loner, and other post-traumatic stress-related conditions.

My parents were overwhelmed by doctor visits, trips to the pharmacy, and the task of constant care at home: the fruitless use of creams, ointments, pills, shots, tar baths, oils, massages, humidifiers, special soaps, special diets, herbs, vitamins, trying different clothes, detergents, and bedding, eliminating molds, dust, etc. Even a number of quacks were consulted, with more time and money wasted on useless remedies including eating only apples and meat, wearing only white clothes and redecorating the house in white, sitting on a vibrating machine, and a nearly fatal treatment containing lye that burned all my skin off. It was all my parents could do to remain optimistic in the face of increasing despair.

When I reflect back on my mother saying "Think of something else", I now understand that she was speaking for herself. She survived my illness by distracting herself with household obsessions, fantasies of my condition

miraculously disappearing overnight, and a passionate concern with pleasing the doctors. My father's coping skills involved hiding in the basement inventing electrical devices in his workshop and a stoic insistence on not letting anything "get to" him. I now understand their behavior as psychological defense mechanisms. At the time, however, I was profoundly disturbed by their inability and unwillingness to directly communicate with me about my condition.

Most published stories focus on people who become ill at some point after a normal life has been established. Their stories show how illness changes their world and forces them to redefine themselves. What then of people like myself who are defined by illness ever since birth, and never get a chance to define themselves otherwise? With temporary illness, emotional trauma heals over time as the body returns to normal. When one is chronically ill from birth, illness IS the norm, creating an inverse of reference points.

Living with chronic illness provokes a mental process similar to the 5 stages that Elizabeth Kubler-Ross outlined for death and dying: Denial and Isolation, Rage, Bargaining, Depression, and Acceptance. The stages emerge in random order, over and over again, perhaps with periods of remission. But then illness rises up again, like the tide, and you are once more inundated and swept away.

There is such a large disparity between my world and yours. Communication from each side must be translated into the other's language, and much is lost in the translation. Emotions are at the heart of the matter, separating doctors from chronically ill patients. Doctors are trained to suppress their feelings, take effective, efficient action, and present an image of decisive competence. In an emergency room this is appropriate; however, the chronically ill require an emotional response. I'm talking about sincere human empathy for physical conditions that must be endured for the rest of your life.

The dilemma between doctor and patient can be described as the ultimate clash of opposites. The patient is sunk into her body, with the mind in danger of being completely submerged. She is drowning, not waving at the doctor, who is sunk into his mind and nearly divorced from his body, which is reduced to a tool for his will.

A doctor's care is especially important when illness must be accepted as a lifelong condition that cannot be cured. To be "in a doctor's care" is to have faith that the doctor cares enough to initiate and facilitate painful but necessary emotional discussions. The ethics of ignoring emotional care for the chronically ill is an issue that must be debated within the medical community.

As a chronically ill child, the doctor was an important role model. My parents and the doctors were my biggest early influences. On one hand I hated them all for ignoring my feelings, and on the other I wanted to be like them, numb to feelings. But it's a bitter lesson taught when a child is discouraged from emotional expression by those before whom she stands naked.

I assume that most people who have a temporary illness go to the doctor open to whatever assistance is presented. I carry 39 years worth of emotional baggage to any doctor's appointment and always show up reluctantly, weighed down by melancholy, suspicion, and resentful resignation. The doctor has no

clue to understanding my apprehension, distrust, and suppressed fury, and has no time for a mournful litany of explanation. Medical schools need to better prepare students for working with patients like me.

Change can be incorporated in two essential ways. First, emotional intelligence should be developed and cultivated in medical school. When traditional medical intervention is ineffective, students must learn to switch to a different model of care, where what *can* be done is to sit down, listen, and sympathetically share the grief, frustration, and rage.

For the last several years, I have been invited by the medical school at the University of California-San Francisco to give a lecture to the new medical students on their first day of class. I applaud this recognition of the pedagogy of suffering, however, the first day of class is quickly forgotten and the patient's perspective is buried under the accumulated weight of lessons deemed more important. Doctor-patient relations should be an entire course that is required of all students.

A second opportunity for change occurs when it is established that a case is chronic. At that point, the patient, along with critically involved family members, deserve to be given options of talking with professionals and/or with someone else who has the same condition. As it is now, families assume that the doctor is taking care of everything, and doctors assume family and friends are providing emotional support. Meanwhile, the emotional needs of the ill person may be ignored unless, or until, he or she is suicidal.

The system needs to consider emotional needs as part of basic care for chronic cases, without pathologizing the situation. It is rational and reasonable to be overwhelmed by the accumulated trauma of severe lifelong illness. To function despite disease, access to emotional support is imperative for mental health.

Despite the fact that millions of people have severe eczema, I did not meet another until I was 35 years old, and did so only as a result of a personal 5 year outreach effort. I have finally heard from, met, or spoken with over 60 people with severe full-body lifelong eczema. I'm sure that my suffering would have been greatly relieved if I'd been able to talk to them at a younger age. There are questions and stories that can only be fully understood by those who've shared that experience. Everyone in the eczema patient network has felt immeasurable solace in communicating with each other, exchanging support and information.

I always knew that I was not the only one in the world with severe eczema, but only when I actually met and talked to others, discovering how much we had in common, did I realize what I'd been missing. It's comparable to having a black child grow up in a white world without ever meeting another black person. It's crucial to self-esteem to meet others who look like you. And it's important for children to meet adults with the same condition who can confirm that it's possible to survive childhood and function as an adult.

I urge the medical community to take responsibility for assisting chronically ill patients in finding emotional support among peers and

professionals. Doctors and patients actively working together can diminish the human tragedy of chronic illness.