

A Woman Allergic to Almost Everything

'Natural,' 'Organic' a Matter of Life or Death

*By Beth Ann Krier, Times staff writer
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The woman is allergic to so many elements in our environment—creature comforts such as gas heat and tap water—that it is difficult to imagine how she manages to cope at all, much less keep trying to reverse this strange disease.

She is allergic (or hypersensitive; it's not known exactly which) to air pollution, synthetic fibers, ink and other chemicals in reading materials, cold temperatures, pine, nonorganic food, common soaps and laundry detergents, soft plastics, some hard plastics—plus a variety of other things. In short, her body is sensitive to most of the synthetic elements found in our increasingly artificial habitats. And she reacts adversely to many natural elements as well, cold climates presently the most devastating.

Managed to Cope

For years while living in Los Angeles she managed to cope by wearing knee-high boots year round, because the cold (even in air-conditioned buildings in the summer) seemed to cause spasms in the blood vessels in her legs. Last March, when her disease “broke through” in full force, the vessels in her legs became so constricted that oxygen barely reached her tissues and it was feared gangrene would set in. Her allergic reactions all involve blood vessels, whether she's confronted with natural or artificial stimuli.

Dr. Sharon—until March a practicing Westwood psychiatrist, a highly credentialed practitioner reportedly loved by her patients—is suffering from what her doctor calls environmentally triggered vasculitis. Her physician, Dr. William Rea, the Dallas cardiovascular surgeon who operated on former Texas Gov. John Connally after the Kennedy assassination, found himself suffering from the same disease five years ago. After he was able to see the process reversed for him (to oversimplify: by identifying the elements affecting him and removing them from his environments), he established a wing at Dallas' Brookhaven Medical Center. Approximately 200 patients have since been treated in the 20-bed ward. Many cases have been reversed or improved, according to Rea. One patient died.

He Has Seen Worse

Though Dr. Sharon's case is one of the most severe Dr. Rea has treated, he has seen worse. Two patients, who were allergic to roughly the same number of items as Dr. Sharon, suffered coronary spasms and stopped breathing. They were revived and eventually their conditions were improved.

When Dr. Sharon found her condition insufficiently improved by drugs prescribed by a vascular specialist in Los Angeles last spring, she was admitted to the Mayo Clinic as an emergency case. After more testing there, she said, she was diagnosed as having an overactive sympathetic reflex to cold temperatures and given more drugs. On March 24, she entered Brookhaven Medical Center's Environmental Wing and lived essentially in a porcelain room for 2½ months. Through more testing in that controlled environment, she was able to learn many of the substances she can tolerate—bottled water, organic foods, for example—and many of those she must avoid to reverse her disease. As she recalled, "It was the first place I got help other than more vaso-dilator medications, which weren't working very well."

After her stay in Dallas, Dr. Sharon set about testing outside environments in an attempt to find a place where she could safely recuperate and possibly reverse the disease—a task Dr. Rea estimated might take perhaps a year. She tested Santa Fe, N.M., which worked out acceptably outdoors but the house she leased for the summer had a pine ceiling to which she reacted. Other attempts to find acceptable real estate in Santa Fe proved fruitless. She stayed for a while with a friend who lived by the beach in La Jolla, but again found herself too sensitive to the indoor and outdoor environment. After testing five different places, all unsuccessfully, she recently returned for a few days to the home she and her husband, a UCLA professor of physiology, purchased two years ago in Bel-Air, using it as a base from which to contact friends helping her locate a safe place.

"We're going to have to sell the house. It can only be maintained with both of our incomes. My husband is distressed and has been very overloaded through all this. It's not even clear how much longer I can stay here," she said, sitting by the pool, about eight feet away from her interviewer so as to avoid exposure to the chemicals her guest was inevitably wearing in cosmetics, nylon stockings and dry-cleaned clothing.

To make this Bel-Air habitat semi tolerable the three weeks she lasted in it, Dr. Sharon did not sleep inside the house, but rather on an aluminum folding cot outside with cotton and wool blankets in place of a conventional mattress. The pool had been drained of its chlorinated water. A speaker phone was placed outside so she could avoid contact with its plastic. And a metal, wind-up clock

stood nearby on a metal table, encased in cellophane rather than a soft plastic bag to protect it from the dew.

Dr. Sharon was wearing all-cotton clothing which had been laundered in sodium bicarbonate, and though this was a hot summer day she still wore three layers of thick socks under heavy hiking boots. Since the chlorine in tap water affects her negatively, she takes sponge baths in bottled water and hasn't had a normal bath or shower since March. The food she eats is simple and organic, generally uncooked so as to minimize the amount of time she has to spend inside the house.

Muscular-Skeletal Problems

"I was considered a classic case of somebody who underestimated what was wrong," noted the 41-year-old woman, who until her disease incapacitated her was maintaining a full psychiatric practice and devoting one day a week to research. (A Phi Beta Kappa and Sigma Xi Smith College graduate, her undergraduate thesis was in organic chemistry. At Albert Einstein College of Medicine in New York, she became a president of Alpha Omega Alpha, the medical school equivalent of Phi Beta Kappa. During her pediatrics internship at Johns Hopkins Hospital she was concurrently a teaching fellow in pediatrics. And during her psychiatric residency at the Massachusetts Mental Health Center in Boston, she was also a teaching fellow there and a teaching fellow in psychiatry at Harvard Medical School. Among many other honors and memberships in professional societies, she is a fellow of the American Psychiatric Assn. and a diplomate of the American Board of Psychiatry and Neurology.)

Throughout her life, said Dr. Sharon, she has experienced severe physical problems perhaps related to the disease diagnosed in Dallas this spring.

"For a long time I've had muscle pain, tightness, soreness, problems with my muscular-skeletal system—waxing and waning. Some of it goes back to my teens. There was a big increase in the last 10 years. I used to get bumps from eating fish or strawberries, but I never thought of myself as an allergic person. I remember having relatively poor circulation in my hands and feet from the time I was 14. It all seemed to get worse after a ski accident 10 years ago. Sprains stayed inflamed for four months and I became quite sick, very sensitive to heat and cold."

In her view, there seems to be some genetic predisposition and she pointed out, "A lot of people in my family have something wrong with their immune systems."

So over the years, in addition to becoming a doctor, she has spent considerable time as a patient. "I was frequently worked up for rheumatoid arthritis and other crippling collagen diseases," she said.

After the disease worsened somewhat dramatically in March, she saw a vascular specialist in Los Angeles. “For the umpteenth time, I was given a diabetes work-up. My feet were ivory pale, not quite dead white. They looked like diabetic feet, though I wasn’t metabolically diabetic. I was started on medications but didn’t improve. My feet were so cold that when I walked it felt like my bones were going through the floor. I was no longer able to reverse the cold by soaking in hot water. All the little devices I had used to cope simply were not working. The frostbite-like pain suggested tissue deprivation of blood on the road to gangrene.”

“I myself knew allergy can cause almost anything at some level, but this massive constriction of blood vessels?” she asked rhetorically. “At Brookhaven, I entered a kind of another world, their environmental control unit which was isolated from the rest of the hospital, with special air filters, special cleaning materials, special linens, all-organic food. When you arrive, they go through your gear and sort out things that might be toxic, like ink pens, anything with soft plastics, most of the hard plastics, leather with tanning smells, fragrances, soaps, anything in the way of synthetic clothing. If it doesn’t bother you, it may bother someone else in the unit. They don’t pretend the environment is totally free of chemicals, but you get fewer of them and you’re in a better position to single out what you’re sensitive to.”

There, Dr. Sharon fasted for five days on bottled water to start cleansing her system of chemicals. She was placed first in a tile room and then moved to a room of porcelain baked onto steel. Because she reacted to so many elements, she was prohibited a roommate during most of her stay. She found herself to be sensitive even to ink in a magazine or the circulars distributed to patients to describe the hospital routines.

“Patients there are encouraged to learn about their illness, to talk to other patients, and you’re encouraged to become a scientist of your own reactions even if you’re not a doctor already,” she recalled. “Some patients feel they’re made more sensitive, that they couldn’t possibly be allergic to all those things.”

Realism Too Bleak

As one might expect, drastic revisions in lifestyle are required of most patients. Dr. Sharon learned she needed to change almost everything and for a while at least, give up her home, her job and direct contact with friends in unsafe places. (She has, however, continued to help some of her patients by phone and while she was in Los Angeles, a couple of them undergoing crises visited her in her backyard for consultation.)

“They’ve been mothering me a lot,” she said. But how else does she cope? “I cry a lot on schedule. I’m used to living with a horrible level of things right now.”

“I’ve had best friends who think I’m whacking out, even though I’ve never been the type. I think I could do rather well if I could get the safe environment. But there are days when I feel as if I’m on the edge of a cliff and about to be pushed over. If I get the safe environment I can work my way back to physical health and happily be making a contribution again.”

Dr. Rea, she reported, is quite optimistic about such a possibility and would like her to contribute to the research continuing at his unit in Dallas. And herself?

“I guess I’ve always characterized myself as a tough realist,” she said. “But recently I’ve decided that total realism is too bleak for this situation. I’m going to have to abandon it. On the days when I’m not being hit with very much, I’m an optimist. On the days when I’m bombed out sick, I’m not. The optimism is based on the hope that I will get a safe place.

Before she left Los Angeles to stay with a former patient of Dr. Rea’s in Portola Valley west of Palo Alto, Dr. Sharon had tested well at a bluff at Point Dume but couldn’t afford to pay \$400,000 for an empty lot. In Dallas, she had also tested a porcelain trailer made especially for hypersensitive people but found she was allergic to a glue used in its construction. She has considered living in Baja or other areas of Mexico but food there is generally contaminated with pesticides and organic food is difficult to obtain and can’t be taken across the border.

Recently, Karen, a Westwood attorney and friend of Dr. Sharon’s, wrote to members of the West Coast Allergy Society asking if they knew of any places which might meet these criteria:

- Pollution-free air (no significant smog or air pollution from mining, smelting, petroleum, chemical or other industrial wastes).
- A location at least a half-mile, preferably more, from major highways unless there are prevailing winds and the house is upwind of the highway.
- A distance from the spraying and use of herbicides and pesticides.
- A year-round mild temperature (in dry climate, mid-day temperatures in the 50s are acceptable; if damp, in the 60s).
- An organic food source within two hours’ drive.
- A site with no nearby chemical sources, such as parking lots or construction jobs.

- No nearby plants such as pine, cedar, juniper, eucalyptus, fir or spruce trees unless on a purchased property where they could be cut down. Not a high pollen area.
- A setting that should provide excellent air flow around and through house.
- An older structure, at least more than one year old with no remodeling, paint or redecoration within one year.
- No hard vinyls (as in floorings) less than two years old; no unremovable plastic unless Formica or Bakelite.
- No synthetic carpets or furnishings unless they can be removed and restored at Dr. Sharon's expense.
- No exposed interior pine, redwood, cedar, spruce or fir unless more than 10 years old or removable.
- No concrete block in construction or wallboard less than five years old. Adobe, stucco, brick and plaster are acceptable.
- No interior insecticides used in the past three years.
- A supply of unchlorinated water is preferred, otherwise permission to install a water filter is needed.
- A place to sleep out is needed in case of buildup of allergens within the house.

Karen has had quite a number of responses, more empathetic than practical, however.

Pursuit Strategies

In the meantime, Dr. Sharon is pursuing two strategies in her search for a safe place and not doing very well at the one in Portola Valley.

“There's the Good Enough Strategy, finding a place good enough to get better in and keep earning a living in,” she said. “And there's the Wilderness Strategy.”

Each has its dangers. The Good Enough Strategy, she pointed out, runs the risk of perhaps making her just worse enough not to be able to reverse her disease. The Wilderness Strategy means a long period of psycho-social isolation, a draining of her earning capacity and separation from friends. At the moment, she is looking for “a very small town outside of a very small town.”

“There are days when the need for people who care for me and love me is so great, I feel I don't want to go to the wilderness” she explained. “And there are days

when I've been hit with enough chemicals that the wilderness seems the only way."

Dr. William Rea believes that if Dr. Sharon can situate herself in the right place she can indeed reverse her disease.

"It's touch and go at the moment," he said by phone from Dallas, adding that because Dr. Sharon is so cold-sensitive, many places normally recommended for patients have been ruled out.

"I have some patients who don't think twice and go to the wilderness and get it done with. It might take her a year in the wilderness. The problem is she's such a social animal."

Dr. Rea clearly didn't like the idea of Dr. Sharon returning to Los Angeles even briefly. "I didn't think she could tolerate that," he said. "In fact, she proved that to be the case."

As for her disease possibly being psychogenic or psychosomatic, Dr. Rea noted, "I've never bought the idea much that people can bring on a disease with emotional upsets, unless they have an underlying defect in their body metabolism. I think everybody accepts that once a person has the disease process going on, emotions can bend it in either direction."

Increased Sensitivity

And Dr. Rea acknowledged that there is "some divergence of opinion" on how cases such as Dr. Sharon's should be handled. (One Los Angeles vascular specialist, asked for a comment by *The Times* on environmentally triggered vasculitis, replied that he had never heard of such a diagnosis. Though he recognized that exposure to such environmental elements as polyvinyl chloride could be linked to vasculitis and other irregularities, he suggested that the case in question sounded like "a nice piece of journalism with nothing behind it" although he was not familiar with specific details of the case.)

Dr. Rea, however, noted that more and more studies are showing that a large part of the population is affected by pollution and other aspects of our increasingly chemical environment—whether they perceive it or not. He cited the recent findings of the National Cancer Institute which claimed that 80% of cancers are environmentally induced.

“Many people are becoming odor-sensitive to such things as cigarette smoke,” he said. “They’re on their way to becoming chemically sensitive. They can perceive this if they just will. They’re just not listening to their bodies.”

To avoid such problems before they become acute, Dr. Rea recommended four basic steps for everyone:

- Don’t drink public water. Drink spring or bottled water.
- Eat less-contaminated foods, organic-type foods.
- Clean up homes to get rid of synthetic chemicals such as air fresheners.
- Work to clean up outdoor pollution and pesticides.

One of the most significant problems connected with the disease, said Rea, is that it can be so incapacitating that people are unable to continue working. He himself was unable to work until his disease was reversed.

“I can live in the city now and do almost anything I want as long as I don’t get overexposed,” he said. “But I don’t think I could live in Los Angeles.”

I’m beginning to think I can’t return to Los Angeles either, even if it were to Point Dume where the air is better,” Dr. Sharon recently concluded. “But I haven’t yet figured out how to get a widely varied supply of organic food delivered to the wilderness. Maybe I need to take up hunting and farming.”

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Dr. Sharon’s last name has been removed for privacy. It was included in the original print version.

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