

Nightmare of the Universal Reactor

Victims of Rare Illness Allergic to Everything

By Lee Dye, Los Angeles Times

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Two dozen people with severe multiple chemical sensitivity have left the polluted cities and moved to a remote mountain in California. This article appeared on the front page of the Sunday edition of L.A. Times.

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Mount Shasta

After many years of misdiagnosis, Jarrold Hines finally learned the nature of his chronic illness. Doctors had determined that he was a “universal reactor,” meaning Hines was, quite simply, allergic to nearly everything in the environment.

With the fresh diagnosis and a new hope of conquering a disease that at times had left him questioning his own sanity, Hines moved to the edge of the Pacific two years ago, believing that the clean air would cleanse his body and allow him to regain control of his life. While there, friends introduced him to a young woman who shared the same disease. Pat Canon was also a universal reactor, and together they tried to build a new life in a world where even the most common substances poisoned their bodies.

Long Road to Recovery

For Canon, the effort to avoid most foods, nearly all chemicals, and even such ordinary items as upholstered furniture, began to pay off and she started the long road toward recovery.

But for Hines it was too late.

As the months passed, Hines changed, Canon recalled. He could barely eat, and “he became emaciated and gray,” she said. “In the last few months, he seemed to age several years.”

Toward the end, he sat down and penned these words:

“My life is like moving through a nightmare, I begin each day as every other - crying. I cry until I’m too exhausted to cry anymore. Horror washed over me. I have no control over these memories of the violence of the illness to my psyche and feelings of terror, fear, panic and hysteria.”

“They just keep coming at me and I try to face them. But they do not go away. They are a part of me now.”

On May 11 of this year, Jerry Hines made his way back to the banks of the Sacramento River, to a quiet spot where he had spent a lot of time. There, alone, he shot himself to death. He was 38 years old.

Pat Canon moved to this small community at the foot of Mt. Shasta, where she joined about 25 others who share the same disease. They come because the air is relatively clean and because there are a few houses here that have been stripped of nearly all the materials that cause their violent reactions.

But mostly, they come because there are others here who share the same problems, others who understand the torment of living inside a body that is trying to destroy itself.

‘Monastic Life’

“They wind up living a monastic life,” said Dr. T.E. Cleaver, a local physician who has treated several of them. Cleaver admits there is little he can do to help, because the patients are allergic to nearly all drugs.

Most of them are single, since few marriages survive the allergy, and it is almost impossible for them to date, since some of them are even allergic to each other. Almost anything can cause a severe reaction. The list is endless: car exhaust, pesticides, synthetic fabrics, ink, most foods, plastics, chemicals, and so on.

Even slight exposure can cause a wide range of reactions: extreme fatigue, dizziness, confusion, depression, irritability, hyperactivity, headaches, blurred vision, shortness of breath, bloating, spontaneous bruising, chills, skin rashes, mental fuzziness, aching joints, loss of energy, and cardiac and vascular problems,

They sometimes appear to be drunk, Cleaver said, yet they cannot drink because they are allergic to alcohol.

“They get treated like crocks for years,” Cleaver said. “Nobody takes them seriously.”

Fatigue is such a problem that a trip across town is almost overwhelming. Vents in cars must be taped closed, and all synthetic materials removed.

Most of them have gone from one doctor to another, and tried one drug after another, all of which they were allergic to, thus making their problems worse, not better.

Somewhere along the way, the lucky ones ran into someone like Dr. Phyllis L. Saifer of Berkeley. Saifer, a clinical ecologist, is among a handful of physicians around the country who understand the problems of the “universal reactors.”

She had a good reason for specializing in that field. She had the disease herself.

Link to Chemical Exposure

Like many victims - no one knows how many universal reactors there are - Saifer's problems began after major exposure to a chemical. In her case it was formaldehyde, which is used extensively in medical research.

“I lost my memory,” she said. “I just couldn't think.”

Several victims cited similar complaints. Canon, who has a bachelor's degree in literature, said she found that she couldn't read.

“Books had been my whole life,” Canon said, “and I couldn't get through a single paragraph.”

Saifer eventually recovered by limiting her exposure as much as possible. She now spends her time trying to help others who are suffering from the same ailment.

She said in an interview that it damages the body's immune system which appears to be especially vulnerable to “environmental insults.”

Key Role of 'T cells'

The immune system is regulated by a subgroup of white blood cells, called “T cells,” which are very sensitive to radiation, pesticides, certain viruses and drugs, and even mental stress.

“These cells are in charge of the immune department,” she said. “They regulate the immune system. They're the boss, the director.”

“They are supposed to tell the body, ‘That's a virus. Kill it,’ or ‘That's a food, leave it alone,’” she said.

“Laboratory evidence shows that if you expose the regulator cells to severe emotional stress, for example, the number of cells will go down,” she said. Some viruses and chemicals may kill the cells. Women who have been raped or who have suffered some other serious emotional trauma, such as the death of a loved one, experience a temporary drop in regulator cells, Saifer said.

When there are not enough regulator cells, the immune system “goes berserk,” she said, and “we begin to see reactions to everything,”

When the system fails, she said, the body acts as though it is overloaded and seeks to reject everything, even such essentials as food and water.

Suppression of the regulator cells leaves the victim vulnerable to universal reactivity and “the patient may quite literally become allergic to everything in his environment,” Saifer said.

The victim also becomes hypersensitive, reacting to chemicals that would not even be noticed by others.

During one interview, Matt Thompson, who has been here for about a year, became visibly ill because of the presence of a reporter, even though the reporter had showered twice just prior to the interview. Thompson’s eyes grew puffy, his complexion pasty and he began slurring his words while sitting outdoors about 10 feet away.

The reporter had complied with instructions not to wear any scented deodorants, like shaving lotion, and had taken special precautions against provoking reactions.

Acute Sensitivity

Thompson, who had to leave after talking for no more than 20 minutes, concluded that ordinary laundry soaps absorbed by the reporter’s clothing caused his reaction. But it could have been any number of things. Thompson is allergic to Pat Canon, for instance, possibly because her body produces higher quantities of yeast than normal, a common problem among universal reactors.

Sensitivity is so acute that even a plastic table top may cause a reaction. Many materials, including plastics, synthetic fabrics and even metals, have volatile components that evaporate in a process called “outgassing.” These components may be inhaled, causing an allergic reaction.

“Have you ever smelled a new plastic shower curtain?” Saifer asked. The odor the curtain gives off is from “outgassing.”

The only treatment at this point is to reduce the number of “environmental insults” as much as possible - a treatment that Saifer finds grossly inadequate.

“The treatment is lousy,” she said. “Sending people off to the woods is not my idea of an answer.”

While it may be lousy, that treatment, in most cases, seems to work.

Weakened by Disease

Carlye Runyon, 49, a former schoolteacher, sought refuge here three years ago after the disease had confined her to bed, where she spent most of her time crying. The disease had left her so weakened that there were times when she could not hear the phone ringing while sitting right next to it.

She is considerably better today, though far from cured.

“There seems to be an element of time involved,” she said as she sat outside the “chemically safe” duplex she shares with other universal reactors. “Our bodies need to live a less toxic life.”

After two or three years, she said, most people improve.

“If you get away from all these insults and lower the load that the body has to deal with, the immune system may recover,” Dr. Saifer said. “Some healing may go on. You may be able to cope again.”

Runyon, who has a master’s degree in education, is not unlike most of those who have sought the cleaner environment of Mount Shasta in a desperate effort to recover from their disease. Most are bright, well educated, professionally oriented people.

That has led to speculation that the disease is more mental than physical, striking those who are unable to cope with the pressures of life in modern America. Saifer, for one, scoffs at that notion, contending that the Mount Shasta colony is atypical.

“These are the rare birds,” she said.

The most plausible explanation, Saifer contends, is that brighter, better educated people are more likely to discover the true nature of their illness.

Most of the people here seem to have figured it out for themselves after an extensive history of erroneous medical opinions.

“Most of these people have seen a lot of doctors,” Saifer said.

Those who are unable to figure it out stand a good chance of winding up in a mental institution, she added. Or, as Runyon concluded, on skid row.

Self-Diagnosis

Thompson, 29, said repeated responses to various elements led him to conclude - accurately, as it turned out - that he was suffering from extreme allergic reactions to the environment.

“A pattern sets up,” Thompson said. “I found that each time I got behind a diesel truck, I got sick.”

Thompson’s problems are so acute at this stage that he cannot even associate with many other universal reactors. He spends much of his time far up the slopes of Mt. Shasta, alone.

“There’s no one I can be with,” he said.

Not only can the attempt to define the illness be very frustrating for universal reactors, it can be expensive.

Olivia Blatt, who moved here three years ago with her husband and two sons, said she spent \$35,000 trying “to exhaust the possibilities.”

Felt Life Was Over

“Conventional treatment just did me in,” she said. Feeling that her life was over and that “I was going to die,” Blatt turned to Dr. William Rea of the Environmental Health Center in Dallas.

Rea’s clinic treats more than 400 patients a month who are suffering from some form of chemical sensitivity, an affliction he believes is clearly on the rise.

He blames the increase on “massive pollution of our air and water.” He estimated in an interview that at least 30% of the people in this country are “severely affected” by some form of chemical sensitivity, and at least 70% suffer from “some effects.” He said he could not estimate the number of people who are universal reactors.

“We better wake up,” he said. “Ignorance is just too prevalent. People have got to demand answers from their doctors.”

Rea's clinic tries to identify the patient's allergies through selective exposure.

Allergic to everything

The patents are put in a tile room where they fast for several days. Finally, they are fed various foods, one at a time, to test the reaction.

"I was there five weeks," Blatt said. "He stopped testing me because I was allergic to everything."

On the bulletin board at Rea's clinic, Blatt saw an ad for a "chemically free" apartment in Mount Shasta. So her husband quit his lucrative job as a Washington, D.C. attorney and moved the family here.

She said she is gradually getting better, but she misses the fast-paced life style in the nation's capital

"This is a very lonely illness," she said.

She would like to return to Washington, where she worked as a federal contracting officer, but she doubts she ever will.

Her husband, who now makes about a third as much as he made in Washington, loves it here. And her sons, now 8 and 10, have shown early symptoms of the same disease. They may have no choice but to remain in as chemically free an environment as they can find.

Heredity Link Suspected

Blatt, like Saifer and several others interviewed for this story, believes heredity may play a key role. She is convinced that both her parents had the disease, though their cases were less severe, possibly due to lower exposure to toxic chemicals.

Adds Saifer: "I don't believe that everybody is equally vulnerable. That's the heredity factor. Yet there are plenty of cases where people came from good stock and got dumped on with pesticides (and came down with the disease)."

Thus it may well be that there are many people who are vulnerable but have no reason to suspect it because no one in their family was diagnosed as having the disease. It may also be that they and their families lived in less toxic areas.

If they are subjected to a sudden exposure of toxic chemicals, their system may overload.

An Underlying Disease

That should not be allowed to happen, according to Saifer. A reduction in toxic elements would lessen the chances.

“More and more chemicals are bringing out an underlying disease that didn’t have to show up,” she said. Meanwhile, life goes on for a lonely colony whose members, according to Mount Shasta’s Dr. Cleaver, are “amazed to discover that they are surviving.”

Canon, who had just completed her college education when she was struck down by the disease, is quite sure of what the future holds for her.

“I’m going to get better,” she said. “I’m going to be able to use my mind again.”

When that day comes, Canon wants to return to the cities, and there is little doubt that the disease that nearly destroyed her life will continue to play a major role. She will campaign for public awareness of the high cost of toxic chemicals.

Haunted by Memories

She is haunted by memories of the man who shared both her life and her disease. Before he took his own life, Jerry Hines was a “kind, gentle, sensitive man,” Canon said.

“This was a brilliant man, a talented artist,” she said. “He didn’t have to die.”

She looked once again at the note Hines left behind. It ended with this observation:

“Many times I wish to God that my body carried the visual evidence of the social and medical violence done to me, so that I could say to them, ‘Here’s what you did to me.’”

Sidebar

For Victims, Chemical Alert Must Be Constant

Phyllis L. Saifer, M.D., is a clinical ecologist who has suffered from universal reactivity. Here is her description of how she and others combat the disease: “We eat chemically clean, unprocessed foods, avoiding cans, packages, preserved, artificially flavored, artificially colored and synthetic foods. Ideally, we would eat foods that are organically grown, free of chemical pesticides and fertilizers.

“We vary our diet to avoid sensitization to certain foods. Constant daily repetition of foods can induce sensitivity in the susceptible person.

“We avoid unnecessary scents as in toilet paper, household cleaners, cosmetics and room fresheners. We look for unscented cosmetics, deodorants and laundry detergents.”

“We open windows in homes and use chemicals with caution, preferably outdoors.”

“When shopping for new clothes, we read labels and choose the natural fibers over the synthetic. We wash new clothes before wearing to eliminate the formaldehyde permanent press finish and to eliminate excess dye.”

“When choosing a new home, we pick one that has had a chance to outgas at least eight years and that is gas-free.”

“We avoid unnecessary use of drugs and seek alternative therapies.”

“We never spray pesticides in the house.”

“Exercise and regular trips away from the polluted city to clean air at the ocean or in the mountains become a regular part of our lives.”

-Lee Dye

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