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REPORTER'S FILE

# The Long Search for Fibromyalgia Support



Fabrizio Costantini for The New York Times

Judy Robinson has been living with fibromyalgia.

By ANNE UNDERWOOD

Glenn Robinson was always physically affectionate with his wife, Judy. But after she underwent abdominal surgery four years ago, everything changed.

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Long after the incision healed, Judy had pain in her hips, her lower back, her legs, her muscles, her skin. When Glenn tried to tickle or squeeze her, she would shy away. Hugs would elicit a grimace. “Don’t touch me; it hurts,” she would say, backing off. Glenn reacted the way any husband would. “I got angry,” he said.

The couple’s social life ground to a halt. Judy, 48, began begging off picnics, barbecues and trips to

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# 9 to 1

Ratio of women to men seeking treatment for fibromyalgia.

## Multimedia



Patient Voices: Fibromyalgia

the boat races at Belle Isle Park in Detroit, where they live.

“We would make plans to get together with friends for dinner,” said Glenn, 50. “Come that day, beautiful weather, she wouldn’t want to leave the house.”

There were days when Judy didn’t even want to talk on the phone. And though she soldiered through eight-hour workdays in the shipping and receiving department of a leather company, she would take breaks to sit in the bathroom and cry.

The Robinsons became desperate to find out what could possibly be causing Judy’s pain. [M.R.I.’s](#) turned up nothing more than a herniated disc or [osteoarthritis](#). Both can be excruciating, but

neither could account for the pains Judy felt all over her body. Her doctor prescribed narcotics, but even those didn’t help. It hurt to wash her face. It hurt to raise her arm. It hurt to sleep. It still does.

“If you touch my back, it feels like it’s all bruised,” she said. “Lately it’s felt like electroshocks.”

In March 2009, after four years of suffering, Judy finally found a new doctor who could name her ailment: [fibromyalgia](#).

If there is a circle of purgatory that Dante forgot, it might be the one reserved for fibromyalgia sufferers. The problem isn’t just pervasive pain. It’s the challenge of having a condition that is not well understood. It doesn’t help that there is no objective medical test to confirm it — no blood test, no cheek swab, no [X-ray](#) — just a patient’s subjective reports. Nor does it help that there is no cure. Many physicians don’t want to be bothered with incurable patients.

If doctors don’t sympathize, why would friends? How do you explain to people that you have no broken bones or burns or even infections, yet your body hurts all over? You look fine, yet beg off work and social engagements. Are you a malingerer? Are you just trying to claim disability? Are you simply crazy? And why don’t you get better?

“Divorce is a big problem,” said Sharon Waldrop, head of the Fibromyalgia Association of Michigan.

And yet, this is a huge improvement over the situation a few decades ago. Until 1990, when the American College of Rheumatology published diagnostic criteria, fibromyalgia was routinely dismissed as the imaginary sufferings of hysterical, middle-age women.

Muhammad Yunus, a rheumatologist at the [University of Illinois](#) College of Medicine at Peoria, has been a pivotal figure in the field. He published the [first scientific study describing clinical characteristics of the disease](#) in 1981 and [the first genetic linkage study in 1999](#). But when he expressed his initial interest in fibromyalgia in the late 1970s, his mentor discouraged him. “You

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will ruin your academic career by dealing with these crazy people,' ” he said his mentor told him. “ They’re women. They’re complainers. They’re lazy.’ ”

Today, research is validating their suffering, showing that people with fibromyalgia really do process pain differently. The syndrome is recognized by the [World Health Organization](#), the [Centers for Disease Control and Prevention](#), the American College of Rheumatology, the Arthritis Foundation, and the National Institute of [Arthritis](#) and Musculoskeletal and Skin Diseases. The [Food and Drug Administration](#) has approved three drugs to treat it — Lyrica, [Cymbalta](#) and Savella are the brand names — and fibromyalgia has its own diagnostic code for insurance forms.

“Insurance companies don’t have a code number for a disease unless it’s real,” said Dr. Mark Pellegrino, founder of the Ohio Rehab Center in Canton and the author of 15 books on fibromyalgia.

Doctors today have a much better idea of how to treat the ailment — not only with drugs, but also with exercise and measures to improve sleep. And though the suffering never totally goes away, it is possible to vastly reduce the pain and learn to cope with what remains.

Minnie Lee, 37, a financial planner in Playa Del Rey, Calif., is one who has managed successfully. Once bedridden with stabbing pains in her back, she now exercises regularly and has completed half a dozen triathlons. She even writes [a fibromyalgia blog](#) that offers encouragement to other sufferers.

Yet there are still rampant misconceptions, even among physicians.

“A year ago, a doctor told me only women had fibromyalgia,” said Randy Wold, 58, a drag racer and retired auto mechanic from Cypress, Calif., who has suffered from fibromyalgia since the early 1990s. Today he races his 1979 Z 28 Camaro and 1989 Pontiac Firebird with the logo for the National Fibromyalgia Association emblazoned on them and makes an announcement that if there is a man there with pain, he’s willing to talk. Without such support, he says, it can be hard for a man to get a diagnosis.

And no matter what gender the patient is, struggles with insurance companies are common. Lynne Matallana, president and founder of [the National Fibromyalgia Association](#), says many members have complained that insurers make it difficult to receive the approved drugs for fibromyalgia.

“Since these drugs are new, there is no generic version,” she said. “But insurance companies often require that doctors prescribe generics first.”

As a result, patients have to demonstrate that they have failed to respond to cheaper drugs, prescribed off-label for fibromyalgia, before they get the ones that work best.

To Judy Robinson, such complaints are minor, compared with the stress and frustration of living with an undiagnosed disease.

Now that she has finally put a name to her ailment, she has found the right drug to treat it. Equally important, knowing the name of her condition has led her to her local fibromyalgia association, where she and Glenn have gotten emotional support and extensive information.

“Before this,” Glenn said, “I never really understood before what Judy was going through.”

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