

## Fibromyalgia not just in your head

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One doctor told her she was overly sensitive to the workings of her body, another said that, as an oncology nurse, she was associating with her patients through her symptoms.

The subtext was clear. "It was kind of a way of saying, 'It's all in your head.' In other words, I was a hypochondriac," said Betty Razvillas. "I don't look like I'm sick, so I've had co-workers who didn't believe there was anything wrong with me &mdash; that I was a malingerer."

Faced with disbelief, frustrated and dispirited, Razvillas tried for years to find a name for what was causing the pain she felt all over her body and the sleep problems that left her feeling exhausted from the moment she got out of bed.

It wasn't until 1990 that a doctor diagnosed something called fibromyalgia.

A year-and-a-half ago, the debilitating pain, headaches and fatigue had reached a critical point, and she also was suffering from irritable-bowel syndrome, which often is associated with fibromyalgia.

"I started feeling in early 2006 that I wasn't going to be able to work anymore. I was feeling so disabled I was going to have to quit working. I had used all my sick time, all my vacation time, my personal leave. I didn't have any means to manage it anymore. I was in a desperate state," recalled Razvillas, 60.

It was then that she got in to see physician I. Jon Russell, a noted researcher in fibromyalgia. He put her on Lyrica, a drug then in trials and just approved this summer by the Food and Drug Administration as the first drug for the treatment of fibromyalgia.

For the first time, Razvillas felt some relief from the constant pain, and she was able to sleep better.

Turns out, "It is in your head &mdash; and your spinal fluid. Fibromyalgia is a neurologic disorder," said Russell.

The National Fibromyalgia Association estimates about 10 million Americans have fibromyalgia, defined as a chronic condition of pain in muscles, ligaments and tendons also marked by fatigue and disturbed, non-restorative sleep.

In many ways, Russell's 30-year career follows the evolution of thinking and understanding about fibromyalgia. When he was in training at the Mayo Clinic, the implication was that patients' symptoms of chronic, widespread pain were a response to stress and were psychological.

"It implied to patients that it was their fault."

Over the years, Russell, who in addition to a medical degree has a doctorate in biochemistry, has studied the neurological mechanism and epidemiology of the disorder, conducted drug clinical trials and consulted with pharmaceutical companies on drug development.

He noted that Lyrica works by reducing abnormally high levels of Substance P in the spinal fluid of people with fibromyalgia.

All this is relatively new. Until 1990, there were no diagnostic criteria for fibromyalgia and few clinicians focused on it. The American College of Rheumatology published criteria that year, and other medical groups eventually recognized the disorder.

Far from being vague and tough to diagnose, Russell said he finds it easy to identify fibromyalgia. First, the patient must have had pain all over the body for at least three months. Second, a minimum of 11 of 18 tender points around the body must be painful under relatively mild pressure.

Russell, who with registered nurse Jenny Fransen wrote "The Fibromyalgia Help Book: Practical Guide to Living Better with Fibromyalgia," is sometimes asked to sign off that a patient is disabled and unable to work.

But, "I tell patients let's do everything we can to help you rejoin life rather than accept this defeat your body is trying to

pull on you."

Psychiatrist Lesley M. Arnold of the University of Cincinnati College of Medicine, said: "There are still physicians out there who are skeptical about fibromyalgia. Lyrica lends legitimacy in the minds of doctors because the FDA recognizes it as a condition. It's a positive for patients. They'll have more options."

"Lyrica has changed my life," Razvillas said. "I started having a positive outlook and feel better mentally. I rest better. I have more energy, a better mood. I've been able to go back to church, a simple thing like that."

Ambien aids her sleep, and she finds massages and heat pads helpful for pain.

Diet is key in alleviating irritable-bowel symptoms. On days when she isn't well enough to go to the health science center, Razvillas works at home.

"Being an oncology nurse has been my salvation because I can look at my patients and say, that could be me. They come to the doctor with their courage and their smiles and hope, and if I can give them additional hope ... I feel blessed," she says with tears in her eyes.

Coincidentally, Razvillas' husband, Richard, has fibromyalgia as well, suffering more with migraines.

"We support each other," she said. "We get up in the morning and laugh about what is the pain du jour, and it's a contest of who hurts the most. We're a funny pair."

It's the second marriage for both, and together they have five children and 12 grandchildren.

Treatment has made a big difference for Razvillas. But truth be told, it is still a rare day when she feels no pain at all. "As we speak," she said late in the interview, "my knee is throbbing."

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