



# When the Pain Won't Go Away

More women have fibromyalgia than breast cancer, but the disorder is rarely talked about. WD breaks the silence. BY LESLIE GOLDMAN

**I**n 2001, Emily Shaules was an active, happy 25-year-old lawyer living in Chicago when a casual toss of her hair triggered a sudden, excruciating snap in her neck. Fearing she might have torn something or given herself whiplash, she headed to the emergency room, where she was diagnosed with a pulled muscle, prescribed Vicodin, and assured her symptoms would blow over in a week. Instead, the pain began to radiate throughout her body. A month later, she could no longer bear to hug her boyfriend. “Imagine if someone chopped off your finger,” she says. “I felt that level of pain, everywhere.”

Doctors tested Emily for everything from bulging disks and hypothyroidism to lupus and multiple sclerosis—all came back negative. By 2003, she couldn't pick up her 12-pound dog, she had been let go from her job for failing to keep up with the demands, and her relationship was over. “I remember praying that a scan would show a brain tumor, because at least then I would have a concrete diagnosis,” she says. “When no medication will even touch your pain, but all the doctors say nothing is wrong, you start to think you're insane.”

Emily wasn't imagining things. She was finally given an answer: fibromyalgia, a chronic condition with symptoms including widespread pain and tenderness, disrupted sleep, and memory and cognitive troubles (also called “fibro fog”). Six million to 10 million Americans are thought to suffer from

fibromyalgia, and the majority are female. But there's enormous confusion over what fibromyalgia truly is, and no reliable diagnostic tests or cures exist. As a result, women often hear their doctor say something along the lines of what Emily heard: “You'll just have to get used to the pain.”

## HOW IT ALL BEGINS

Many experts believe fibromyalgia is triggered by a physical or emotional trauma—a car crash, a divorce, a sexual assault—that sends the body into fight-or-flight mode. But even something as simple as Emily's twist of her head can bring it on. “Normally, the sympathetic nervous system turns on to prepare the body for a stressful

situation, tightening the muscles and connective tissue to increase their strength, then shutting off when the threat is gone,” says Ginevra Liptan, M.D., author of *The FibroManual: A Complete Fibromyalgia Treatment Guide for You and Your Doctor*. But with fibromyalgia, the brain gets stuck and the stress response never stops, like a smoke alarm sounding without a fire.

Over time, a chronically activated sympathetic nervous system can cause chaos throughout the body, keeping muscles tense (leading to pain and tenderness), preventing deep sleep, and ultimately prompting pain-sensing nerves to crank up their signals.

## WEIGHT FACTOR

Obese fibromyalgia patients report more medical problems, take more medications, and are more prone to depressive symptoms than patients of a healthier weight.

## A DIFFICULT DIAGNOSIS

With well-recognized conditions like cancer and diabetes, doctors have tools like biopsies and blood glucose tests to help make a concrete diagnosis. With fibromyalgia, many doctors are still using criteria that originated in 1990, which calls for them to press on 18 spots (including specific points on the neck, elbows, back, and knees). “If the patient is tender in 11 of the 18 spots, and other causes have

TOP LEFT: ISTOCK; GETTY IMAGES (8).

## REDUCE THE PAIN

Try these strategies for coping.

### Get moving

A recent *Annals of Rheumatic Diseases* review of nearly 400 studies found that exercise reduced pain in people with fibromyalgia more than medications or other treatments. Gentle cardio like walking eases pain, improves sleep, lessens fatigue, and helps you shed pounds; weight-bearing activity strengthens muscles; and stretching increases range of motion.

### Find a release

Fibromyalgia can cause painful knots in muscles and fascia (the connective tissue around muscles). Myofascial release is a technique in which a practitioner slowly stretches your fascia, similar to stretching a piece of taffy. This can speed healing and lower inflammation. To find a provider, go to [mfrtherapists.com](http://mfrtherapists.com).

### Cut out certain foods

Dairy and gluten can be highly inflammatory for some people (eggs, corn, and soy can too). Eliminate them for three to six months to see if there's any improvement and to help you detect what may be a trigger.

SOURCES: Susan Blum, M.D., M.P.H., assistant clinical professor of preventive medicine, Icahn School of Medicine, Mount Sinai in New York, author of *The Immune System Recovery Plan*. Akiko Okifuji, Ph.D., psychologist, chronic pain specialist, University of Utah.

been ruled out, you diagnose them with fibromyalgia,” says Dr. Liptan. In 2010, the American College of Rheumatology stopped recommending the tender-spot exam because of its subjective nature (a patient may feel sore in 13 spots one day and only 10 the next) and added “fatigue” and “brain fog” to the criteria—along with all-over pain lasting three to six months that can’t be explained by another diagnosis.

Complicating matters, fibromyalgia often coexists with other conditions, like irritable bowel syndrome and migraines. (Doctors focusing on these conditions may miss fibromyalgia.)

Once a diagnosis is finally made—studies show that the process usually takes between two and 10 years—patients must still contend with the fact that “some people mistakenly believe fibromyalgia is a psychological disease and that it’s ‘all in your head,’” says Tarvez Tucker, M.D., professor of neurology at Oregon Health and Sciences University in Portland.

### WHY WOMEN?

Although the role of estrogen in pain syndromes is complex, higher levels of estrogen during pregnancy can be protective against childbirth pain. In contrast, when estrogen levels are low, such as at the onset of the menstrual cycle or in menopause, many women experience more sensitivity to pain.

Not surprisingly, fibromyalgia often shows up in women between ages 40 and 55. And sufferers still in their childbearing years often say their pain worsens just before and during their periods, when estrogen nosedives. There’s a genetic component too: Fibromyalgia tends to run in families.

### SEARCHING FOR RELIEF

A handful of medications attempt to dull pain signals in the brain, but they don’t seem to improve other fibromyalgia symptoms like



### JUST BREATHE

Light forms of yoga help your muscles relax. If you have fibromyalgia, avoid variations that have “power” or “hot” in the name—these types can actually aggravate symptoms.

fatigue or brain fog.

Antidepressants may help, because the pain and mood centers of the brain overlap, so treating the latter, even in depression-free patients, can sometimes improve pain.

For Servanne Edlund, 40, a mom of two from Silver Lake, MN, a combination of a nerve-blocking drug and an antidepressant helped lift the pain that led to her diagnosis five years ago. “I felt better almost immediately—more energy, improved sleep, and less pain,” she says. “I started walking as much as two miles every morning. Before medication, I couldn’t get down the stairs.” Certain lifestyle changes hold promise too. (See sidebar, *left*.)

For Emily, now 41 and living in Asheville, NC, relief came through a combination of diet and mind-body relaxation techniques. She follows an anti-inflammatory diet filled with fruits, vegetables, and fish, meditates 10 to 15 minutes a day, and sleeps eight hours a night. “The pain has lessened immensely, plus the meditation helps lengthen my fuse, so I don’t get upset at little things that used to bother me when I was in pain,” she says. “I’ve learned that there can be health and happiness after fibromyalgia.”