

For decades I've been in agony, yet no one believed me. Now I'm finally getting the help I need—and so is my daughter

by Carolyn Bishop,
as told to Barbara Brody

living in pain



Carolyn and her daughter, Aubrey, both suffer from fibromyalgia.

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I'M STANDING IN MY doctor's office watching my 12-year-old daughter wince as he presses on her elbow joint. She's having a tender point exam, which involves pressing on 18 specific points on the body, basically to see how much it hurts. The doctor doesn't use much pressure—about the same as pushing your thumb against something to the point where the nail bed just starts to turn white.

To most people this wouldn't feel uncomfortable, but by the time the test is over Aubrey is in so much pain that she's in tears. Her diagnosis: fibromyalgia. While I hate to see her so upset, I am relieved beyond belief. At least Aubrey won't have to spend decades trying to convince people that she's sick, like I did.

My strange symptoms started in my early teens: neck and shoulder pain, a chronic runny nose and flulike achiness. I was always exhausted but couldn't sleep. I started high school as an honor student, but I was so tired that I couldn't keep up. My doctor tested me for various viruses and diseases, but he couldn't find anything wrong. Since the pain was most intense in my left shoulder blade, he diagnosed me with tension headaches.

I made it through the days by taking OTC painkillers (like ibuprofen) and resting a lot, and shortly after high school I got married and started a family. But in my 30s new symptoms started to crop up. I had severe bladder pain—just walking was excruciating—but I didn't have a urinary tract infection. And I developed a tingling, burning sensation in my hands and feet that made it feel like I was walking on sharp cement. After doing some digging online, I thought that I might have interstitial cystitis (IC), a condition that causes intense bladder pain, but my doctor told me I didn't. At first I trusted his judgment, (Please turn to 72)

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CONTINUED but I just knew something wasn't right.

As I continued looking for answers online, I read that most people with IC also had fibromyalgia—and that fatigue coupled with pain in your hands, feet, shoulders and neck are tell-tale fibromyalgia symptoms. I was convinced this was my problem, but my doctor didn't agree; he just wrote me a prescription to help ease the pain.

desperate for help

My job as a software designer became very difficult. I was exhausted and my back and neck ached, so it was hard to sit in front of a computer all day. I also had to run to the bathroom every five minutes. I started calling in sick a lot.

I begged my doctor, "Please figure out what's wrong, because I'm missing too much work." "Well, don't miss work," he told me. "You're just depressed." When my project ended in 2002, I decided not to look for a new position.

It strained my family emotionally and financially, but my husband, Ron, was absolutely amazing. He did all the grocery shopping and housecleaning, picked the kids up from school, and took them to and from their activities. At the time, Ron was in school getting a master's degree, so our standard of living dropped dramatically. But we managed.

My son, Matt, who was a freshman in high school, really had a hard time accepting that I was sick, and he resented the fact that I couldn't do things that other moms did. I used

defining fibromyalgia

What are the symptoms? They vary but may include: all-over achiness, pain, stiffness and tenderness in the muscles and joints; overwhelming fatigue; chronic headaches; difficulty sleeping; trouble concentrating, disorganized thinking and forgetfulness; and depression or anxiety.

What causes it? No one knows for sure, but that may soon change. The latest research indicates that fibromyalgia may be a central nervous system disorder, not an autoimmune condition as previously suspected. In one study, scientists at the University of Michigan applied pressure to the thumbs of fibromyalgia patients and healthy participants and asked them to tell them when it hurt. The fibromyalgia patients reported pain at much lower levels of pressure—and functional MRIs showed that areas of their brains involved in pain processing were activated at those levels, says Lesley M. Arnold, MD, director of the Women's Health Research Program at the University of Cincinnati College of Medicine, who specializes in fibromyalgia.

How is it diagnosed? If you have symptoms for more than three months, talk to your primary care doctor. He may administer a tender point test and/or refer you to a specialist (such as a sleep specialist, rheumatologist, neurologist and/or psychiatrist) to rule out other conditions.

For more information Visit the National Fibromyalgia Association website at fmaware.org

to be very active, and now I couldn't get off the sofa without being overcome by pain.

One night when I was up late writing on the computer (journaling helped me cope), Matt came into the living room, saw me and got angry. He thought that if I could stay up late I wasn't really sick; he didn't realize that I was up because I couldn't fall asleep. Aubrey was just the opposite: She'd often sit with me on the sofa, hold *(Please turn to 76)*

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CONTINUED my hand and ask if she could make me some tea.

In 2004, after about a year of being out of work, I decided to file for SSI (social security income). My family didn't have any health insurance, so I was desperate.

To verify my claim, I was sent to a new internist. When I told him that I couldn't work because I had fibromyalgia, he said, "I can't put that down." I asked why not, and he told me that he couldn't "medically differentiate between fibromyalgia and laziness." I was shocked.

believing me at last

Just when I was starting to feel hopeless, I came across a website that mentioned a doctor in my area who specializes in fibromyalgia. When I called to make an appointment, I got more encouraging news: I might be eligible to participate in a trial for a drug called Lyrica.

The first step was to have the tender point test. To be diagnosed, you need to respond to at least 11 out of 18 tender points; I reacted to 17.

When the nurse told me that I had fibromyalgia, I started crying. Finally, someone was taking me seri-

a new treatment option

About 5 million American adults (most of them women) have fibromyalgia, says Dr. Arnold. Many are given a variety of pain relievers (including antidepressants that have pain-relieving effects) and drugs that improve sleep, but these don't help everyone. Now there's another option, Lyrica, the first medication to be specifically FDA-approved for fibromyalgia. Lyrica is a type of pain reliever that reduces pain signals from the nerves to the brain. About one-third of patients who try it have a substantial reduction in pain, says Dr. Arnold. (About half have a noticeable but not as great improvement.) There can be side effects, the most common of which are dizziness and sedation. Other potential ones: weight gain, swelling of the hands and feet, and allergic reactions, which can range from blisters and hives to rare but severe swelling of the tongue and breathing problems.

ously. Lyrica isn't a miracle cure, but as soon as I started taking it, I began to feel better. The minute I noticed that Aubrey had dark circles under her eyes and started complaining that her shoulders and knees hurt, I suspected she had fibromyalgia, too.

Once Aubrey was diagnosed, she started taking Lyrica as well as a number of other drugs and supplements. We've both worked closely with our doctors to come up with a combination of treatments that works best for each of us. I take about 22 pills every day (four prescription medications and a slew of vitamins and supplements), and Aubrey takes about the same. It's cumbersome, but

it's helping. I'm back at work and have changed careers: I'm a drug technician and am also studying to be drug and alcohol counselor.

I do worry about Aubrey being on some of these drugs at such a young age, since a few are relatively new and haven't been tested in adolescents. And there have been other challenges: Because she's so tired, she went from being in all honors classes to failing almost everything. (We finally decided to homeschool her, which is working out very well.) But for the most part, she's getting to be a normal kid. Best of all, she won't have to spend decades in pain wondering what's wrong. **wd**

