

Good Housekeeping

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My Story



by Elizabeth A. Browning, Founder and CEO of LLuminari®

Most people would be surprised to learn I have fibromyalgia. I exercise regularly, maintain a busy schedule and am energetic by nature. I've definitely come a long way since I was first diagnosed 14 years ago when few people had heard of the disease and even fewer knew how to diagnose it. It hasn't been an easy journey, but perhaps my story will help you believe that better days are ahead.

My journey begins

One Saturday in the summer of 1994, a girlfriend and I drove our sons to summer camp. I will never forget that day. The sun was shining, the boys were excited and so were we. For us, taking the boys to their first sleep-away camp to spend a week away from their parents was an important life transition both for them and for us. My girlfriend and I laughed and cried a bit, taking a few pictures of the boys sitting on their bunk beds before heading home.

Shortly before reaching home, I felt ill—like I was “coming down with something” due to my flu-like symptoms, yet it seemed quite odd in the middle of summer. My symptoms included a scratchy throat, itchy eyes, and achy muscles, but they were also coupled with an overwhelming exhaustion unlike any I'd ever experienced. As a result, I went to bed—for the rest of the weekend! Although my suspected flu never developed, my symptoms didn't subside. In fact by Monday the exhaustion worsened to the point that I could only work two to three hours each day and slept the rest of the time. My appetite disappeared. I alternated between diarrhea and constipation. And my muscles painfully ached.

I shared my list of flu-like symptoms with one doctor after another to no avail. My family doctor tested me for virtually every disease associated with these symptoms and yet, the tests always came back negative. Eventually, after dropping from a healthy 125 pounds to a skeletal 95 pounds, he ordered an AIDS test for me. I was devastated. Truly I longed for a diagnosis to validate that my condition wasn't only “in my head”, but the prospect of being diagnosed with AIDS was frightening. My life had already changed dramatically. I could no longer run five miles a day or effectively balance my challenging work schedule with my family responsibilities. I'd become a mere shadow of my former self, physically, mentally and emotionally.

Fortunately, the AIDS test was negative. I was both relieved and depressed at the results, because my illness was still not resolved. Then one day, more than a year after that summer day when I first felt ill and following endless rounds of doctor appointments and more tests, a rheumatologist diagnosed my condition as fibromyalgia. The good news was my condition now had a name, but unfortunately, no one knew its cause or how to cure it. In fact the diagnosis did not rely on a definitive test; rather it was based on a medical consensus on the syndrome's cluster of symptoms and the number of painful points. These points were numerous and painful beyond description. I'll never forget that just pushing on my hips triggered explosive pain.

Accepting, yet still coping

Looking back, recovery required accepting my condition and slowly learning to live with it. During this time I came to know my body better than ever. I could readily recognize the onset of symptoms. Eventually I knew what triggered my outbreaks and how to avoid them.

For the first three years I gave up all aerobic exercise because it seemed to initiate a flare-up. Later I realized it was the physical stress of the exercise that caused the episode. Knowing this enabled me to gradually increase my tolerance for exercise, pacing myself, doing a little at one time rather than trying to do a lot at once. The same was true with my emotional health. I knew an emotionally-charged discussion or argument with my sons or husband could trigger a relapse and send me to bed for days. Moreover, mood swings, depression, and irritable bowel syndrome accompanied these episodes. But eventually, I was able to anticipate these stressful episodes to better manage my life so the time increased between occurrences and the severity of symptoms lessened.

During the past 14 years, I've learned a lot about myself, my body and fibromyalgia, including ways to cope with its challenges. Today I am physically active, enjoying biking and running, as well as managing a demanding professional schedule. I know a relapse can occur any time and sometimes does, when I push too hard, encounter too much stress for a prolonged period or when my sleep cycle becomes disrupted. To help me handle life's ups and downs and in turn, my

condition, I've created a personal checklist for taking care of myself, and one that I hope you find useful in your quest to face the challenges of fibromyalgia head on.

Living with fibromyalgia

- Learn and remain mindful of what triggers a relapse
- Listen to your body—recognize early symptoms
- Cut back on your schedule if you find life's demands and stressors are too much to handle
- Keep your doctor informed, and particularly if you experience any new or unusual symptoms or the frequency of flare-ups increases
- Exercise regularly, but at a moderate pace—don't overdo it
- Eat healthy foods, including fruits, vegetables and whole grains—and avoid too much sugar
- Tell your family and co-workers about your condition and ask for their assistance whenever you need it
- Throw away the guilt—celebrate and enjoy all you do to the best of your ability
- Record your remarkable journey using audio tapes or writing in a personal journal

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