

# "my mystery disease"

For 14 years, my unrelenting pain had every doctor stumped

by Cynthia Toussaint, as told to Jennifer Haupt



When I think about my life in the fall of 1982, before my injury, I still can't believe how lucky I was. A 21-year-old college student working toward a degree in dance at the University of California, Irvine, I had just found out that I was up for a part in the TV show *Fame*. My dream of being a professional performer was on the verge of becoming reality.

But about a month after the audition, I was performing a routine dance move during ballet class when my right hamstring snapped. I felt a painful burning sensation radiating through the back of my right leg, into my back and buttocks. By that evening, the pain had become so excruciating that I couldn't sit or lie down on my right side. About three days later, my leg turned purple and became swollen and cold.

An internist at UCI Medical Center confirmed I had torn my hamstring, but he reassured me that I'd be dancing

**NAME:** Cynthia Toussaint  
**AGE:** 45  
**HOME:** Los Angeles  
**PROFESSION:** Founder and director of For Grace, a nonprofit organization

soon, and prescribed crutches and mild painkillers. Within a few weeks, however, I began to suspect this was no minor injury.

The pain grew to the point where my leg would shake uncontrollably when I tried even the simplest moves. I couldn't understand what was going on with my body, and it soon seemed that neither could anyone else. *(Please turn to 110)*

## MY ADVICE

- Seek out fellow chronic pain sufferers through online discussion boards and support groups at medical centers.
- Know that everything you're experiencing is real and normal, including depression, stress and anxiety.
- Be open to alternative therapies, such as acupuncture, biofeedback, guided imagery and aromatherapy. There's no one-size-fits-all cure.
- Remember, you're responsible for your own well-being.

## MY MYSTERY DISEASE

Continued

### unrelenting pain

Over the next year, I went to many doctors who assured me that if I kept stretching my muscles, the pain would subside. But in April 1983, I had to drop out of school because I could no longer keep up with my rigorous dance class schedule. Despite my injury, I took a job performing in an illusionist's act in Reno and Las Vegas. I thought I'd be OK because the routines weren't strenuous, and I iced my leg every night before I went on stage.

But by 1984, two years after the initial injury, my dance career was finished. The pain had worsened and spread to my pelvis, left leg, arms, trunk and vocal cords. I'll never forget staring in the mirror one night before going on stage, looking at my body and saying, "It's all over."

Over the next five years, I continued to search for a specialist who could explain my condition, but every doctor I saw was mystified. One told me I had stage fright; another said I was just trying to get attention.

My college boyfriend, John, stuck by my side, and in 1990 we moved to Los Angeles. By then, the pain had spread throughout my entire body, save my eyes. I was bedridden most of the time. John had to feed me,



Cynthia and her fiancé, John, the one person who stood by her throughout her illness.

bathe me, even bring me a bowl to urinate in. For five years, I was in so much pain that we couldn't make love. I was so grateful for his support, but I felt helpless and humiliated.

### a mystery unraveled

In 1996, a reporter who was interviewing me about chronic pain told me about Edward Carden, M.D., a pain management specialist at the University of Southern California. I made an appointment, but after years of searching for an answer, I didn't have high hopes. Imagine my shock when, after hearing my symptoms, Dr. Carden said he recognized the burning sensation as a sign of Reflex Sympathetic Dystrophy (RSD), a chronic neurological condition that causes severe pain. (See "What Is RSD?" *above*.)

Dr. Carden told me that although my RSD could not be cured because it had been untreated for so many years, there are ways to manage the pain. One option is to surgically implant a pain-controlling device, such as a morphine pump or a spinal cord stimulator, but I didn't think my body could endure the strain. Instead, I opted for prescription medication, physical therapy and psychological counseling to combat the depression I'd been battling for years.

I tried a variety of painkillers and antiseizure drugs (commonly used for neuropathic pain) until we found a combination that worked. Each day I started to feel a little stronger and lighter, like a weight had been lifted off me. The hardest part was teaching my body that it was OK to move again. My arms and legs had folded into a permanent fetal position, and I had to visualize movement and practice relaxation exercises before I could lift my arms or legs.

## what is rsd?

### Reflex Sympathetic Dystrophy (RSD)

is a chronic neurological condition that typically begins after an injury and is caused by an overactive nervous system. The disease often goes undiagnosed and untreated, leaving sufferers with debilitating chronic pain. It's estimated that RSD afflicts between 200,000 and 1.2 million people in the United States. Symptoms of RSD include:

- Severe burning pain, which may radiate to other areas of the body
- Extreme skin sensitivity
- Changes in skin temperature, color or texture
- Swelling and stiffness
- Changes in hair and nail growth
- Decreased mobility in the affected area

For more information, visit the Reflex Sympathetic Dystrophy Syndrome Association at [rsds.org](http://rsds.org).

### making progress

Within a month of beginning treatment, my body and my world miraculously began to open up. Soon I was able to get out of my wheelchair and walk for the first time in three years—not for miles, but for a good 50 feet. I finally began to recognize in myself the vibrant woman I had once been.

Now that I'm no longer a slave to the pain, I've dedicated my life to standing up for the millions of women with RSD and other chronic pain syndromes who are fighting to be believed. In 2002, I launched For Grace ([forgrace.org](http://forgrace.org)), a nonprofit organization that is devoted to the ethical and equal treatment of all women who are in pain.

In 2005, I returned to UC Irvine to complete my dance degree from my wheelchair, 23 years after sustaining the ballet injury that triggered my RSD. One of my projects was choreographing my pain experience for a ballerina to perform. Being back in the dance studio was a dream come true. Although I'll never be completely healed physically, I'm finally emotionally whole again. **wd**