

Carmen's Story

Category: Stories

written by Carmen Diaz | October 10, 2008

Carmen Diaz

I used to be a shy woman who didn't like the spotlight and never did any public speaking. Ovarian cancer has changed all that. Now I look for opportunities to tell my story.

I am a 62-year-old, Puerto Rican-born, New York-raised mother of two. I was diagnosed with ovarian cancer in 2004. But for more than a year before that, my symptoms weren't recognized.

In January 2003, I started to suffer from abdominal discomfort, back pain, indigestion and heartburn. My primary-care physician told me to change my diet and prescribed medication for my indigestion. After weeks with no improvement, I went to a gastroenterologist, who diagnosed gallstones. In March, I had gallbladder surgery.

Most people go back to work within ten days, but it took me a month. My fatigue, heartburn and stomach cramps, I was told, were probably a result of the surgery. Over the following months, I kept returning to my primary-care doctor, who prescribed antacids. Eventually, fearing that he'd brand me a hypochondriac, I stopped going.

That fall, during a routine gynecological check-up, I told my ob-gyn that I was feeling pelvic pressure and a burning sensation in my bladder. My pelvic exam and Pap smear revealed no abnormalities; she told me I had a urinary-tract infection and prescribed antibiotics.

By early 2004, I was having trouble eating: even after small meals, I felt full and bloated, and my stomach swelled. Family members began to ask jokingly if I were pregnant.

All my life, I'd been an avid tennis player and skier and exercised regularly. Now, fatigue and shortness of breath forced me to cut back on my workouts. My primary-care physician ordered a stress test, electrocardiogram and blood tests, which showed that I was anemic, so I took iron pills and began to feel better.

I hired a personal trainer to concentrate on abdominal exercises. After several weeks, though, I realized that no amount of training was going to reduce my stomach. That April, determined to get my flat stomach back, I had a tummy tuck.

A few weeks later, the right side of my abdomen began to bulge. "It's probably a hematoma—residual blood," my plastic surgeon said, but he also ordered a CT scan and a blood test for CA125, a tumor marker.

The results were shocking: my abdomen was filled with fluid, and my CA125 was

sky-high.

My plastic surgeon delivered the news: I had stage IIIC ovarian cancer that had metastasized to my pelvis, lymph nodes, bowel and liver. I was so stunned, I can barely remember a thing he said.

He also informed my primary-care doctor, whom I'd known for fifteen years. When I went to see him the next day, he was devastated. "I don't know how I'm going to talk to Carmen about this," he'd told his wife.

We spent a long time discussing the cancer. Reviewing my healthy lifestyle, he told me, "You did everything you were supposed to do." And he had already made an appointment for me to see a wonderful surgeon that very afternoon, so I couldn't be angry with him.

I do feel angry at my gynecologist, though. When I'd told her that I was having a tummy tuck because of my distended belly, she'd never mentioned the possibility of ovarian cancer; she'd only commented, "The next time I see you, you're going to have a nice, flat stomach." And when I told her about the cancer diagnosis, she only said that ovarian cancer is very hard to detect.

She made me feel that there was nothing anyone could have done, but I don't believe that. I feel so mad that I was misdiagnosed so many times. If I'd known about the symptoms of ovarian cancer, I could have gotten help earlier.

A month after being diagnosed, I had a total hysterectomy with debulking, followed by six rounds of Taxol and Carboplatin. Eight months later, a second-look surgery revealed more cancer cells. Cisplatin, delivered directly into my abdominal cavity, made me so ill that I had to be hospitalized for ten days. I went into remission for ten months.

Then, in April of 2006, more than a year after my hysterectomy, my pelvic pain started again. After negative MRI and PET scans, the doctor said that the pain might be caused by adhesions.

In June, during a procedure to remove them, one of my intestines got punctured, so the surgeons had to reopen my abdomen. They detected some microscopic cancer cells, and I started yet another round of chemo—six months of Doxil and Gemzar this time.

This past summer, eight months after I'd finished the chemo, they found a tumor in my liver. In August I had a part of my liver resected, and I'm still recuperating. I'll be starting six rounds of chemo next week. Once you have ovarian cancer, it's a never-ending cycle of remissions and recurrences.

How do I cope? I have a lot of faith, and I get strength from prayer and from my family's support. And I never think about my illness. Even when I'm having chemo, people tell me, "You don't look sick." I always believe that I'm going to beat this disease.

Because of my experiences, I decided to become a volunteer at SHARE: Self-Help for Women with Breast or Ovarian Cancer (www.sharecancersupport.org). I

offer counseling in English or Spanish over the SHARE hotline, because I want to help women who have ovarian cancer not to feel so alone.

I was always shy, but after SHARE sent me to a public speaking class, I went to Philadelphia and spoke before 200 physician assistants. *The Today Show* has taped me speaking to students at Mt. Sinai Medical Center, and I've gone to Washington, DC, to talk with New York Senators Clinton and Schumer about research funding. I also speak to Latina women in Spanish Harlem and Queens.

Every year I visit several medical schools. "Every woman can have these symptoms, but persistent symptoms are a red flag," I tell students. "If a woman has them for more than three weeks, I want you to think about ovarian cancer."

Unfortunately, my story is not unique. I try to live each day of my life as fully as possible. And I am committed to helping other women who face symptoms like mine: I share my personal experiences so that they won't have to go through what I did.

About the author:

Carmen Diaz is a mother of two and grandmother of four. For many years she worked at NYU Law School as an administrator before retiring in 2004 after being diagnosed with ovarian cancer. She now volunteers for the Ovarian Cancer National Alliance (www.ovariancancer.org) and the SHARE hotline (866-53SHARE).

Story editor:

Diane Guernsey