Cancer Health™

Spunk and Spirit to Spare

With a sense of humor and a warm heart, Carol Tietz, an 11-year survivor of small-cell lung cancer, pays her good fortune forward.

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One morning near the end of 2009, Carol Tietz woke up to find she had lost her voice. She didn't think much of it because she had been volunteering at a noisy Christmas market the night before. But when she still couldn't get a sound out two weeks later, her husband, Randy, encouraged her to see a doctor.

The longtime resident of Tinley Park, Illinois, now 73, went to an ear, nose and throat specialist who ran a scope down her throat and found that Tietz's left vocal cord was paralyzed. In early January 2010, after a follow-up CT scan of her lungs, an MRI and a biopsy of her lymph nodes, she was told the cause: She had small-cell lung cancer (SCLC) in her left lung.

The diagnosis didn't surprise her. "I had been smoking forever—since I was 16 years old," she says. "I didn't know the first thing about small-cell lung cancer as compared to non-small-cell, but I knew it was the smoker's cancer." She had smoked throughout her 30 years at the NBC affiliate TV station in Chicago where she worked until her early retirement in the early 2000s. And she had already cut back quite a bit from those days, when she was "a two-pack-a-day girl." But the day of her diagnosis, she says, "I just said, 'That's it. I'm done," and she quit cold turkey.

Each year, about 235,000 Americans are diagnosed with lung cancer. There are two main types: small-cell and non-small cell. In small-cell, malignant cancer cells form in the tissues of the lung. It is less common than non-small-cell, accounting for only about 13% of diagnoses, compared with 86% for non-small-cell. Treatment options, as in Tietz's case, often include chemotherapy and radiation.

The Treatment: Chemo and Two Kinds of Radiation

Fortunately, the cancer didn't appear to have spread from Tietz's left lung. At the time, doctors weren't using a staging system for SCLC, but even for disease that hasn't spread beyond the lungs, the course of treatment is grueling. Tietz found an oncologist she liked—"I have to have a doctor with a sense of humor"—and started her chemotherapy in February 2010. The chemo treatments, six in all, consisted of three days of IV infusions with two drugs, followed by 18 days off.

"Like everybody else, when I was on the chemo, everything tasted like metal," she recalls. The only two things she could eat were macaroni salad with a mix of Miracle Whip and mayo and peas, and apple fritters. “I loved apple fritters,” she says. Randy made the macaroni salad, bought the apple fritters and drove her to all of her appointments. “He was a great caretaker through this whole experience,” she says.

She did OK, she says, until the end, when both her red and white blood cell levels dropped very low. She was given two pints of blood to replenish the red cells and an injection to boost her white cell count. Such side effects of chemotherapy are relatively common.

After she finished up the chemo, Tietz had radiation every weekday—33 chest treatments, followed by 15 cranial ones (to prevent brain metastases). For the cranial radiation, “they made a formfitting mask over my whole head, and then they would literally screw me in to the table,” she says. “It’s not for anybody who is claustrophobic.”

Fortunately, she isn’t, and the treatments weren’t painful. The hardest part was the tedium, she says. “What took a long time was lining you up and making sure that the radiation was going where it was supposed to.” But the nurses—for both the radiation treatments and the chemo—were wonderful, she adds.

Follow-up tests after the chemo and radiation treatments found no cancer, and Tietz has remained cancer-free for 11 years and counting. She is particularly grateful for her response, given that the five-year survival rate for SCLC is 7%. “I have no complaint.” Her only follow-up now is a free annual low-dose CT scan of her lungs.

Paying It Forward

Her first thoughts, posttreatment? “There goes my hair, for starters,” she says. “It was just starting to come back when I did the brain radiation, at which time, my hair said, ‘The hell with you, lady!’ It never really came back to speak of, so I wear hats all the time.”

Although her doctors warned her that her voice might not return, it did, but it wasn’t as deep as it had been. As a result, people stopped thinking they were speaking to a man when she answered the phone. Her brain was unaffected; she didn’t experience memory or speech issues, as sometimes happens with cranial radiation.

Tietz’s good fortune has motivated her to help others. She spied a brochure for the Lung Cancer Alliance (now called the GO2 Foundation for Lung Cancer) in her oncologist’s office and contacted the organization to see whether it held group meetings she could attend.

“I looked them up because there’s not a lot of us—small-cell people—running around,” she says. She went to Washington, DC, with the group to help lobby Congress for more funding for lung cancer, since other cancers kill fewer people but get more funding, she notes. She also became a phone buddy—someone other people with SCLC can talk to and ask questions.

She also volunteers as a phone buddy for Imerman Angels, a support organization that connects people who have cancer with those who have had the same type of malignancy. And she participated in a group at a nearby Gilda’s Club before the coronavirus pandemic closed it down. (Gilda’s Club, “where no one faces cancer alone,” was founded in 1995 to honor Saturday Night original cast member Gilda Radner, who died of ovarian cancer in 1989, and is now known as the Red Door Community.)

For Tietz, the low points have been the deaths of many of her phone buddies. “I’ve had at least 30 phone buddies, and I’ve lost a lot of them over the years,” she says. “But I’ve been very fortunate that I’ve had families call and tell me how grateful they were that I helped their mothers—usually it’s a woman about my own age—and that makes me feel better.” Currently, she has two buddies, one who is doing OK, one who is not.

“I basically try to get people to do things that they enjoy,” she says. “Because I think that’s a serious part of treatment for the disease—not to dwell on it but to look positively and laugh and have some fun. Because you’re going to make it or you’re not.”

During her own treatment, when she had to get a blood test every Sunday, she wound up at a hospital near a Ronald McDonald House (which provides temporary housing for kids undergoing cancer treatment and their families) and a children’s hospital. “I thought, I’m 62 years old, and I’ve lived a full life. I’ve had a lot of fun. I’ve gone around almost all over the world, at least all over Europe. I have nothing to complain about. And look at those little kids in there fighting cancer,” she recalls. “So I just figured, if I make it, good; if not, I’ve had a great life.”

Tietz’s philosophic outlook guides her in helping others, and it helped her remain engaged and positive throughout her own cancer journey. She’d probably tell you she was more inclined to count her blessings than to bemoan her fate.