When science fails a scientist

In August 2012, a phone call from Scotland told me that my sister had been diagnosed with advanced breast cancer. Six weeks later she was dead. In between was a blur of travel, family tensions, and—one bright spot—making my sister laugh one more time. But my sharpest memory of those weeks is the helplessness of sitting in a hospital office learning that estrogen receptor-negative breast cancer cells in my sister’s body had metastasized to her bones, lungs, and brain. We could make her comfortable, the doctor said. That was it.

When I learned about my sister’s cancer, I was in the midst of a career transition—the second in my professional life. Back in my 30s, I had decided to leave the bench because I felt I could have a greater impact on the human condition as a medical research foundation administrator than I could as a decent, but not great, neuroscientist. For 6 years, I was the chief scientific officer of a foundation that researched drug treatments for benign but deforming tumors that could become malignant. I was the one sitting at the other end of the table, facing people who were relying on science to change, and possibly save, the life of their loved one. “We are going to get there,” I would say. “We will find drugs that will work.” I truly believed it.

I got the news about my sister after my husband and I had taken the radical step of moving from a city-centered life to the rural one we had fallen in love with. I was working from our new home, consulting for cancer foundations and walking my dog in the woods at lunchtime. For the first time, my career had slowed down. I was quietly torn between fully embracing this change and returning to the career fast track, but I couldn’t quite figure out what it was that I missed. Was it the prestige, the salary, or leading the charge to find cancer treatments? Traveling to our annual international conference 6 years straight (always at the time of my June wedding anniversary)? Strategizing with 30 researchers and clinicians about curing brain tumors (which caused me to miss a celebration dear to my in-laws)?

“First, the helplessness grew. Then the anger: Why was hospice the only option she had? Weren’t there off-label drugs or clinical trials? Shouldn’t I know this? Had my sister been in denial? How could she not know she was riddled with cancer? She’d feared breast exams, so she didn’t get them. We’d argued about that, and about her smoking. Eventually, my anger gave way to resignation: Her cancer had simply eluded the options science had to offer.

We knew my mother’s large family had a history of breast and ovarian cancer, and one cousin had a BRCA1 mutation. But it wasn’t until after my sister’s death that I investigated and mapped the family cancer tree. When my gynecologist saw it, she said wow. We’ll never know if my sister had a BRCA1 mutation, but the summer after she died I learned that I did. The decision to have prophylactic surgery was easy.

Science may have helped me protect my health, but I no longer assume that we’ll have translated enough science into better drugs for cancer if I ever need them. Meanwhile, this difficult couple of years has helped me make peace with my decision to abandon the high-profile career ladder. Just a year before she died, my sister had retired and she was looking forward to freedom. So my decision has been to grab life—now. At 50, I finally have a work-life balance. I found a job in mental health administration where I can make an intellectual contribution, and which also allows me to go home and live life. I have given enough to the “cures” cause. It is a long road, and it is time for others to lead the way.

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Editor's Summary

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