

## Ten Months: One Patient's Story of Stage IV Cancer

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*Disclosures of potential conflicts of interest may be found at the end of this article.*

In an unfamiliar, dimly lit hospital hallway, I waited for my doctor's phone call. I had always been so healthy that I could not imagine the news would be bad. When the phone rang, I walked down the hallway to speak with my doctor out of earshot of the receptionist.

"I am sorry," she said. "The news is not good. The CT scan shows masses in your abdomen. It is likely they are not benign."

I didn't know what to say. She sounded anxious and young. I remember resisting the urge to comfort her, and fragments of our conversation:

"You probably have ovarian cancer," she told me. "You should see a specialist. . . tomorrow, if possible. Are you there by yourself? Is there someone at home? Can you get home by yourself?"

Barely out of the hospital parking lot, I started crying. At points along the three-mile drive home in the blackness of a February evening, I sobbed. Practically no one in my family had had cancer. It was something I had never expected. My husband, Ward, is 20 years older than I am. We had assumed I would outlive him. Now that seemed uncertain.

Driving, blurry with tears, I thought of my life: growing up with my two brothers on the edge of West Philadelphia; my parents and all they had provided me; my two oldest friends, with whom I'd played with dolls, gone to school, biked, sang, tried out for sports teams, fought, made up. I thought about college, prior work as a plant science lab technician, two summers as a farm worker. Then there were my graduate studies in ecology and genetics and, later, science policy. I remembered when I decided to become a high school biology teacher, and particular students whose lives I had changed. My thoughts turned to Ward and my grown step-daughter Maggie.

I might not survive this disease, but I had already done some good in the world. I had mattered. Yes, my life had been worth living. I could die and know that I had made a difference. Was that enough? No. I wasn't ready. I couldn't die.

But, at that moment, I knew I might.

The next day was a Thursday and I went to work as though I hadn't spent the previous evening crying. I pretended that nothing had changed and taught my classes while Ward spent the day trying to get me an appointment at a cancer center. In Advanced Placement Biology, students performed the final steps of isolating a protein from genetically modified bacteria. In Introductory Biology, I continued teaching my students steps

to study patterns of genetic inheritance. I cleaned the classroom, putting things away, organizing the small corner of the world I could actually control.

Through the efforts of my doctor and Ward, I had an appointment scheduled four days later. The medical oncologist wore a colorful shirt and jacket with a flower lapel pin. He greeted Ward and me warmly at the start of the appointment and explained that my condition was not good. The surgeon arrived later, wearing scrubs. She efficiently presented her analysis. Based on the scan and my absence of symptoms, they both believed the cancer was slow-growing and could be removed by surgery. Six rounds of follow-up "chemo" would clean things up. They emphasized how successful this treatment had been for thousands of women. They were an energetic and confident duo. The oncologist placed his hand reassuringly on my arm: "We will help you survive this," he said.

The surgical plan changed unexpectedly. Two days after that first visit, I began throwing up. Four days later I was constipated and in pain, my abdomen swelling with fluid produced by the cancer. The pain became so severe I was admitted to the hospital. A scan followed, and it showed extensive disease, much more than had been thought. I required my first paracentesis, and watched as more than two liters of fluid were removed from my abdomen. The medical team decided to postpone surgery and start chemotherapy instead.

Three rounds of paclitaxel and carboplatin followed. The abdominal fluid was supposed to dry up, but didn't. Weekly, I visited Interventional Radiology to have liters drained. I was nauseated from the chemotherapy and exhausted from the nausea. Thinner as the weeks passed and losing hair, I looked bird-like. Baby ostrich, a friend said. My oncologist offered to order that a catheter be placed in my abdomen so I wouldn't need to go to IR, but another friend had told me about someone who had died of ovarian cancer. Close to the end, she drained liters of fluid daily. I feared that having that type of drain would mean that I was dying. Would cause me to die. I refused the drain. Cancer fed magical thinking, superstition.

I spent most of the month in bed. From our bedroom, I watched branches on trees sway, snow fall, birds and squirrels forage, snow melt. My days were organized around taking medicines, trying to eat, sleeping. Ward told family and friends how much I loved paper cards sent through the mail and I began to receive several each day, from relatives, friends, colleagues, students. Yes, I mattered, and because of this I was willing to live

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through each difficult day. Friends helped organize a schedule of meals, visitors. Daily, a friend would come over for a couple of hours, relieving Ward, and providing me with news of the world beyond my sickness. Helping the long-term substitute teacher who replaced me gave me occasional small tasks that reminded me of my former life.

Ward forced me to walk. With the disease symptoms advancing, I wanted to give up. The internal fluid pressed against my organs and I struggled to sit, to stand, to eat, to breathe. I wanted to be left alone. But Ward, angry, fearful, and with deep love, would not let me be. So, I bundled up for slow walks down the path into the woods next to our house. Despite myself, I knew he was right and I kept walking, every day that I could. Over the weeks, the snow melted. The ponds filled. Ward and I listened to a crowd of frogs celebrating a warm afternoon. I discovered pink lady slippers where I had never seen them before. Other early spring flowers emerged. I heard the calls of migrant birds arriving to nest.

The trees were just beginning to leaf out around the time my surgery was scheduled in late April. My parents had already come up twice from Philadelphia and they arrived again on the day of the surgery. The Gyn/Onc fellow who would assist appeared briefly next to my stretcher in the surgical prep area while the operating room was being cleaned. I told her that I wondered how they would find cancer that might be hidden behind an organ. "The very first thing we do," she said, "is to reach in and feel all around." I felt odd. Strangers reaching in, touching my organs, lifting organs from where they rested. I felt scared when she said that they might open me and decide there was too much cancer to operate. Later, my surgeon appeared and gripped my hand securely. It would be all right.

Waking after the surgery, I was moved from stretcher onto bed, but then lifted, swinging towards the ceiling. I cried out in pain. Someone explained that they were weighing me. It seemed dark in the room. The voice was sorry, but each patient had to be weighed upon arrival. Then my parents were at the doorway. And Ward. The surgery was over. My parents would see me tomorrow and left for their rooms at Beacon House. Did Ward stay with me that night in the hospital? I am not sure. But he was there many nights over the next 12 days.

As long as it was available to me, I tracked time by how soon I could press the morphine button. Caring nurses rotated on and off their shifts. Kind nursing assistants helped to bathe me. I memorized their names by studying the whiteboard in my room. A crowd of flowers from friends brightened the tables. My surgeon came to check on me. She termed the surgery a success: they were able to extract much of the cancer even though there was more than they had expected. Chemotherapy would treat the numerous cancer nodules too tiny to remove.

At first, my recovery went smoothly, but 3 days in, my intestines rebelled and stopped working. Once the ileus occurred, Ward made me walk. He would unplug the nasal-gastric tube from the wall and we would circle the hallways of the floor. There were a couple of other patients who walked: a woman who told me that she had been fighting the tumors for 20 years, and another woman, younger than me, accompanied by her parents. I felt immediate kinship although we were strangers. Ward and I walked. And waited. The nurses, social worker, and chaplain all reassured me that I would get through this. In

the moments when I could pull myself away from my preoccupation with my body, I worried about my parents, who came each morning and watched and waited for me to improve. Days passed before my intestines recovered and went back to work. I returned to eating carefully, with some saltines, juice, and a tiny bit of chocolate cake that Ward brought to the hospital on my 46th birthday. Finally, I was discharged with an incision from sternum to pubic bone bisecting my abdomen and a surgical drain in place.

The first week after my discharge, I made great progress. I ate normal food. I took slow walks along our driveway. A nurse visited to check my wound. I carefully poured out fluid from the abdominal drain several times a day. My mother stayed a week longer than we had planned to help care for me while Ward worked and then she, too, returned to Philadelphia. A day or two after she had left, I threw up. Constant nausea prevented me from eating. The sight of food made me sick. Ward brought me plates of tiny turkey sandwiches and dabs of avocado. He alternated between worry and anger as I began to starve. My mind and body were at war. Even as I felt myself disappearing, I could not make myself eat. Ward insisted I contact the hospital.

As usual, my oncologist walked briskly into the examination room. He shook Ward's hand. He gave me a hug. Expecting him to ask about my nausea, I was surprised when he said, "I am worried about what I saw on the CT scan from last week. The cancer has grown very fast since your surgery a month ago. It looks like it might be growing into your liver and on your colon." I don't remember precisely what he said next, but he was very clear.

There were two choices. Continuing the same treatment would not work and I would die, perhaps in a few months, maybe sooner. Or I could try a new chemo protocol, in which case he wanted me to start immediately. As Ward and my oncologist talked, my poorly nourished mind slowly, weakly weighed what had been said. Finally, I was able to speak.

I started chemotherapy that evening in the hospital. Although I threw up when I lifted the lid of the dinner tray, the next morning, I surprised myself by eating a normal breakfast. The anti-nausea drugs given with the chemo were working. That morning, a palliative care nurse came to my room. I had thought that palliative care was part of hospice, treatment for the dying. The nurse explained that it was a specialty focused on symptom management. She diagnosed me as having anticipatory nausea and explained how I could take anti-anxiety and appetite-inducing medications to help my mind accept food. Patiently, she listened to Ward's and my fears and helped us imagine steps that we could take at home to improve my healing. We found her comforting, her information helpful. Still, Ward and I agreed that we would shield my parents by referring to symptom management specialists rather than palliative care, in case they had the same association with hospice.

I left the hospital reassured by the care I had received, but worried about whether the new chemotherapy would work. I expected to fill with fluid again. While at the hospital, my remaining surgical drain became dislodged and was removed. The nurses assured me I would be fine until it could be replaced.

Back at home that weekend, we celebrated my step-daughter's birthday. Like magic, I was eating, enjoying foods again, as though there had never been a problem.

I went back to the hospital the next week to have a more permanent drain inserted into my abdomen. When a resident came out to find me in the crowded waiting room, she invited Ward to come along. The medical team examined me by ultrasound for only a few minutes before they announced that there was no need for a drain—the fluid was gone. My cancer’s activity was dropping; a chemotherapy miracle. I was elated. My body felt more like my own again.

As an outpatient, I met with a palliative care doctor. Ward and I were feeling tentatively hopeful that the cancer was responding to the new chemotherapy yet we were both anxious about whether this progress would continue. The doctor seemed well-informed about my patient history, but clearly wanted to get to know Ward and me: our relationship, how we viewed the last few months, and concerns we had for the next few weeks. I mentioned that I had decided I needed a summer project to distract me from my illness, but had found that I was still too weak to do much other than reading. She asked about my interests, what I used to do, what I hoped to do as I felt better. We told her that at night we distracted ourselves by watching *The Wire*. Captivated by our enthusiasm for the series, she jotted down the title in her notebook.

The 2<sup>nd</sup> time Ward and I met my palliative care doctor, she asked me about my end of life plans. Something about the way she asked made me feel comfortable explaining to her that I didn’t fear death so much as the pain that came before death. I had always imagined being buried in a sack, but then I had seen an ancient Peruvian skeleton tucked in a crouching position in a burial basket. The anthropologist showing Ward and me the skeleton said that she imagined the person ready to spring into the afterlife. Although entirely agnostic, I told my doctor that this was now how I imagined myself at death. She was clearly engaged by the story. She listened carefully, and shared some of her own insights to help me grapple with the uncertainty of my illness.

Over the following months, my CA125 levels normalized and CT scans showed the nodules shrinking. This new treatment was working. Three rounds. Six rounds. Eight rounds. Ten rounds. Through it all, I was getting stronger. But it seemed to me that it wasn’t only science that was saving my life.

Every day, a different friend would visit and I would cling to their reports from the world since I so wanted to be a part of it again. I continued to eat, to walk. Students raised money for a non-profit in my name. My brothers and their families came to see me. My yoga class bought me a pot of New Guinea impatiens and other friends gave us potted flowers so our front door was surrounded by color. Friends kept dropping off dinners for us in a blue cooler that we had first put outside in February. Friends continued to help clean our house. Cards kept coming. Masses were said for me. A client of my father’s sent

holy water from Lourdes. I slept covered by a prayer blanket from one of my Texas aunts and a quilt made by a friend that had a Miraculous Mary medal sewn into it. I hadn’t been able to read during February, but when a friend asked if I had chemo brain, I picked up a book just to prove that I didn’t. After that, I kept on reading, cherishing the endless hours much as I had when I was a child on summer vacation. When I was finally strong enough, I began walking in the woods again.

As I felt better, I longed to return to work. Ward worried that I would prioritize my students and my classroom over my health, him, and our life together. With the uncertain future of my illness, I wanted to seize the present and return part time to work that I love, yet Ward expressed his serious concerns, which our palliative care doctor carefully considered. Still in treatment, I realized that I would need to be conscious each day of finding balance between work and rest. I would have to accept limitations that were not part of my former life.

From my medical oncologist I learned there is no way of knowing how much time I have. My cancer will recur. A remission may last years—or a month. Should my current treatment fail, there are other treatments and trials to consider. He reassured me that if there were no further treatments that would help me, he would do everything to make sure that I suffered as little as possible. Even as we talked, I couldn’t help but search for hope. Was there really no chance that I could be cured?

“If you die when you are in your 80s from a heart attack,” my oncologist said, “and I am at your funeral, then I will say, yes, you were cured of ovarian cancer.”

It made me think of a notebook that a friend gave me just after my diagnosis. My palliative care doctor noticed it once, and had asked about it. I explained that it was my cancer journal—something I planned to throw away once I was done with cancer.

I prefer this ending, but I now realize that the real story is that a lifetime of this illness is in front of me.

To some extent, my change in circumstance and my story is unremarkable. So many people develop cancer. Each of my doctors has had innumerable patients. Yet, for each of us, a diagnosis is shocking. Treatment is difficult. Alongside the medical interventions required over the last 10 months, the efforts of my caring doctors to understand *my* cancer story have helped me survive.

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