

Trifecta: Running on Hope

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October 1983

I had just celebrated my 27th birthday, but there was little joy in the celebration. For many months I had dragged myself through my workdays, college courses, housekeeping, and marriage. I thought I must have a dreadful case of the flu, especially when my back began to feel as if the flesh was being slowly torn away from my ribs. When I could no longer breathe, I risked admitting illness. Nothing could have prepared me for the truth.

December 6, 1983

Excerpt from Oncologist's Hospital Discharge Notes

History of Present Illness: *The patient is a 27-year-old woman admitted to ... Hospital for continuing treatment of her T-cell lymphoma and evaluation and treatment of her post-spinal tap headache.*

The patient was admitted [early in October 1983] in pericardial tamponade. On evaluation, the patient was found to have a very large mediastinal mass and, on biopsy, this was a diffuse lymphocytic lymphoma. Immunologic studies revealed the patient to have a T-cell lymphoma, and subsequent evaluation showed involvement of the marrow.

After some discussion with a variety of people and review of the literature, it was elected to treat the patient with a regimen of high dose CHOP chemotherapy for induction of her lymphoma ... The patient tolerated the treatment quite well, had significant myelosuppression and required support with platelets, blood and antibiotics for approximately one week until her bone marrow recovered. The patient was also given two doses of intrathecal methotrexate, one on 10-28-83 and the second on 11-12-83. The patient did note a significant post-spinal tap headache from the last spinal tap and this persisted and continues on the day of admission. Except for the post-spinal tap headache, the patient feels extremely well, no respiratory complaints, no shortness of breath, and no new problems.

... The patient had significant nausea and vomiting for one to two days after the chemotherapy but then felt quite well. The patient's post-spinal tap headache gradually resolved with the use of abdominal binder and increased oral fluids. After one week in the hospital, the patient had no spinal headache whatsoever, and this did not return.

The patient was observed in the hospital: her white [blood cell count] continued to fall and at the time of discharge was 1300 with a platelet count of 115,000. However, as the patient was quite anxious to go home and was absolutely afebrile, it was elected to allow the patient to leave with the

understanding that she should return immediately, should there be any symptoms of illness or any fever. The patient is well aware of these restrictions.

I had survived the pericardial-window surgery to relieve the pressure on my heart and could breathe again. I had tolerated the megadoses of chemotherapy, and the mass had all but disappeared. I wrapped my mind around the concept of my perhaps imminent death, and the double-whammy of what the oncologist called "involvement of the marrow," which translated into "acute lymphocytic leukemia." In October, I had been told I had a week to live. I was discharged from the hospital on December 6th, walking away from the poisons and the needles and the pain. Christmas was coming. I had things to do.

Yet some nightmares have a way of lingering long after we are awake, and it would be years before this one would end. Initially, *no one* would lay odds on my winning. Hospitalized again, for more chemotherapy, in January of 1984, a series of tearful visitors came to say goodbye, although none of them used that word. Their red eyes, sobs, and sniffles were daubed and stifled while they were with me, but I could hear them in the hallway outside my room. I thought myself lucky to be so loved that people were that torn up about what we had all been told was likely to be my imminent departure. They didn't know I was a dark horse. Neither did I.

September 24, 1984

This was my first day at my new job at a major university. I was still on chemotherapy, and an Intensive Care Unit nurse who had become an extraordinarily good friend came to my office to administer the injections because I had grown too fearful of needles to inject myself.

I needed health insurance for the long haul, and this job was the only way to get it. My marriage was in trouble, so I could not count on my husband's coverage indefinitely. Now virtually uninsurable, I had to leave my career as a private investigator to find a group policy so large that my coverage would be automatic. I had found it and landed a job as a clerk in a computer center. Now all I had to do was learn how to thrive in the new world of computers.

May 12, 2003

Excerpt from Plastic Surgeon's Notes

Chief Complaint: *Right breast cancer.*

History of Present Illness: *This is a 46-year-old divorced woman who works as a consultant for Information Technology. This patient had abnormalities seen on her*

mammogram. She had right breast calcifications and the stereotactic biopsy was done 03/27/03, which showed ductal carcinoma in situ on the right. She also had an ultrasound of her left breast that did demonstrate a lesion at 6 o'clock in the posterior depth. The patient is nulliparous. She is now approximately a 34B bra cup size and she desires about the same ... The patient is now [scheduled] for bilateral mastectomy and immediate DIEP flap reconstruction.

Past Medical History: Persistent for endocrine, history of Grave's disease. She is status post-I-125 radiation ablation therapy times two. She is currently hypothyroid and taking Levothyroid. Respiratory: No history of asthma, wheezing, or dyspnea on exertion. Cardiovascular: The patient had some chest pain in 07/99, was ruled out for a myocardial infarction. She had an exercise treadmill test and she also underwent an echocardiogram that showed ventricular size and function to be normal and a mildly thickened mitral valve with a trace to mild mitral regurgitation. She has a trace to mild tricuspid regurgitation. The patient also has a history of T-cell lymphoma and acute lymphocytic leukemia in 1983. She had also some pericarditis and underwent a pericardial window. She is status postirradiation treatment to her left thorax and also her brain and she is status postchemotherapy treatment with methotrexate and she is presently in remission. The patient also had a history of transient ischemic attack, a series of four of them in one week in 1986 and has had none since. No history of hepatitis or heartburn. No history of kidney or bladder problems.

The cardiac episode in 1999 was, on reflection, probably an acute anxiety attack. I had been working a full-time job, a part-time job, and studying for a master's degree in organizational management. It was a heavy load, and I was under considerable pressure by a number of external forces on both jobs, as well as my own internal desire to succeed academically.

The 20 years between 1983 and 2003 had not been uneventful, but I was still going full gallop when I received news that the mammogram results were abnormal. Everyone had said, "If you have to have breast cancer, 'ductal carcinoma in situ' is the best possible diagnosis." I wasn't worried about what they had found in the right breast. I was worried about what the ultrasound had found in the left breast. That's why I had insisted on bilateral mastectomies, even though I'd been told a less disfiguring partial excision would suffice.

My inner voice was screaming at me to have the breasts off. I did not, at that time, understand that even without breasts, the same breast cancer could occur in other organs. Even though I know this now, I would not have changed my decision if I had known then. Had I not opted for the bilateral mastectomies, they would not have found the invasion into my sentinel node. By the time they would otherwise have found it, would it even have been found before it was too late?

June 4, 2003

Excerpt from Surgical Pathology

Microscopic Description: *The left breast has an invasive carcinoma and lymph node metastasis involving only the sentinel node. An additional 10 nodes are found in the*

axillary dissection, thus 1/11 nodes is positive. The right breast has only DS, grade 2, papillary type. No invasion is seen, confirmed with SMMHC immunohistochemistry. Only the sentinel node is sampled on the right.

March 2012

End-stage T-cell lymphoma, acute lymphocytic leukemia, stage 2 breast cancer. Even better than a lucky bet at the racetrack, 29 years later, this dark horse is still racing—and it looks like she's still winning. The end stage did not end me, the leukemia did not kill me; and this month I celebrated 9 years of life as a breast cancer survivor. So far, so good.

Writing this piece, a sliver of 19th century rural Lithuanian superstition creeps in suggesting that maybe I'm jinxing my survival just by thinking that I've won this somatic contest. Ancestral voices? The same that said, "Children are to be seen and not heard"?

I am surprised to still be in the race, and people ask me how that came to be—as if I really know. I don't know; I can only guess: I'm obstinate, I come from sturdy stock, and I'm ambitious. Even when I was lying on what people had assured me was my deathbed, I was determined to finish crocheting the afghan I'd begun, read the remaining chapters of *The Mirror Crack'd*, and write the thank-you letters to the many people who had shown me enormous kindness.

Delicacy is a trait that neither my mind nor my body was permitted as a child. One was either strong or broken beyond repair; the choice was subliminal, reflexive. So, apparently, was my body's biochemical response, which bathed my young brain and body in stress hormones and set me up for a lifetime of hyperstress in even the most banal situations.

To *appear* strong meant survival, and that is the mode in which my siblings and I were raised on the harsh heels of our immigrant grandparents' and our first-generation-American parents' childrearing methods. To actually *be* as strong as was necessary would have meant somehow having control of those biochemical processes. I didn't. Not until I was a mature woman did I even have an idea that they exist, and not until decades after that did I learn of their importance and potential for long-term, harmful effects to my autoimmune system.¹

My biochemistry did not overreact; it was an appropriate response to a chronic state of fight-or-flight while living in households where we were told we were loved, but hands were not always gentle, fists often took flight at people as well as objects, voices were loud, words were meant to hurt, and a child's sexuality was not her own.

While recently at a routine gynecologic visit, the medical assistant went through her usual routine of weighing me, and asking about smoking, alcohol consumption, and allergies to medications. She added an unexpected question, "In the last six months, have you experienced any domestic violence?" I responded, "Not in the last six months." Then she took my blood pressure, and it was higher than I've ever seen it before. She looked at me wide-eyed. I took a deep breath to ease my angst and explained that the damage of domestic violence does not disappear after six months, six years, or even six decades. I suggested she might want to consider asking questions about domestic violence *after* taking patients' blood pressure. It was

a pleasant conversation; she was just following someone else's orders to include the question, but timing can be everything. Given a few minutes to recover from the flashback triggered by the question, my BP later measured 116/70, not bad for a middle-aged, postmenopausal woman who had minutes earlier relived an age-five beating that left her incontinent and huddled on the floor of her parents' living room.

Summer 1962; Chicago, Illinois

Mom died a year ago of a stroke following a high-risk sixth pregnancy. She was only 44. My chain-smoking, alcoholic, PTSD-suffering World War II Veteran dad dove into a bottle and stayed there, intermittently, long enough for us to have been sometimes placed in other homes. He was trying to hold it together, but he couldn't.

He was, however, still working, and he'd managed to afford to buy me a new pair of shoes, which I had worn to school that day. While playing at recess, the buckle broke. I'd dragged the shoe along with me as I walked home from school that afternoon, in fear of what would happen when dad saw that it was broken. He was so angry all the time, and now that my older brother had run away from home, dad's rage was bottled up and nearing explosion. I could feel it building in him, capped like a gusher by his silence.

The minute he saw the broken buckle, he went for the barber's strap, and I knew what was coming. There was nowhere to hide. The beating lasted for less than a minute in real time, but it also lasted for a lifetime. It seemed like forever before I was allowed to return to school, but by then the ringing in my left ear had stopped. Dad never beat me like that again. As soon as he had finished, the look on his face was one of such shame and sorrow that it hurt me even more than the blows from the barber's strap.

Today

Healing is a miraculous thing. I marvel at those who choose it as a profession. No one looking at me today would ever suspect the ordeal my life has been, which makes me treat everyone I encounter as if they are also as damaged as I am, or worse. One just cannot tell by glancing at the exterior. I am astonished by how well my body has cleanly knit the many incisions made by the needles and surgical instruments, but healing the underlying spirit is far less tidy.

They say there are five stages to grief: 1) denial, 2) anger, 3) bargaining, 4) depression, and 5) acceptance. I've grieved the loss of my mother, father while living, and father in death.

I've grieved the loss of my marriage, my birthplace, and the integrity of my body. The denial phase is never long for me—a minute or two at most, since I have seen so much loss that I know when denial is futile. Anger, too, is short-lived, and I've never seen the point to playing the “if only I had” game of bargaining. Depression, on the other hand, can be a faithful companion even though I have long since accepted all of the many losses of my life. I live—for the most part—in “intellectual” rather than “emotional” mode, just too stubborn to cave in to the crashing defeat that an emotional meltdown signals to me. Despite my best efforts, they sometimes happen too—though less often now than when I was younger.

There is something even more powerful than obstinacy, heredity, and ambition. During the October 1983 ordeal, one physician made a world of difference by saying aloud what I wanted to believe, “You're not dying; you're still living.” Wow! Profound. Life-changing. It was as if he had plucked the words right out of my head. He affirmed my right to hope, that fragile, elusive entity that still remained after all the evils of the world had been loosed upon me from Pandora's box.

Although I'm still in the race, it would be a mistake to think it's an easy one. Pandora's box was opened early in my childhood with abandonment, sexual, emotional, and physical abuse, and neglect, now increasingly recognized as being translated into biochemical responses that damaged my immune system and my ability to handle normal stressors in normal ways, and exacerbated by the myriad of environmental factors that are part of the evils of the modern world.

There are scars—all kinds of scars. Most days I wonder how much longer my luck will hold, but all I can do is keep running. I fill my days with work, with friends and family, with the many small pleasures that give me joy. I try to give my body what it needs to be well, and my mind the peace it needs to work in harmony with the rest of me. I treat others gently because I suspect they have suffered, too. Of course I know I cannot live forever, but—for now—furlong after furlong, each stride is driven by hope. ❖

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Reference

1. Dube SR, Fairweather D, Pearson WF, Felitti VJ, Anda RF, Croft JB. Cumulative childhood stress and autoimmune diseases in adults. *Psychosom Med* 2009 Feb;71(2):243-50.

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Hope for Tomorrow

Learn from yesterday, live for today, hope for tomorrow. The important thing is not to stop questioning.

— Albert Einstein, 1879-1955, physicist 1921 Nobel Laureate