

## No One Gets Out Alive Anyway

By Ellen Holtzman

On a Sunday in April 2008 my husband Bob and I get in the car and head for Mt. Auburn Hospital in Cambridge, Massachusetts. Bob maneuvers our Toyota into a small parking spot right in front of the hospital. A sharp wind hits our cheeks as we slam the car doors shut. Undeterred by the cold, we pull on our hats and get ready for our usual Sunday walk.

First, we stroll along the narrow streets by the hospital and notice a few brave daffodils that have poked their heads up in front of the graceful Victorian homes. Then we walk along the Charles River, as we often do. Sitting on a bench, we watch a college crew team glide through the water on their way back to the boathouse. The wind picks up. So we hurry back to the car and drive home.

The next day rain, pelting the bedroom window, wakes me up. When I sit up in bed, I feel chilled and realize that I am shaking. I lean over to the table next to the bed, pull out the thermometer and stick it in my mouth. I do a double take when I see my temperature, 102 degrees.

I keep the thermometer close to the bed, because a high fever is a symptom of lymphoma, a disease I had in 2001 and then again in 2007. Both times I was sick, I got in the habit of taking my temperature when I started to shake with the chills, downing two Tylenol, and then huddling under the blankets until the fever came down.

But even before I developed lymphoma, I had been diagnosed with Chronic Lymphatic Leukemia, a disease typically found in elderly men; at the time, I was a 41 year old woman with a two year old son at home.

Dr. Barry, a Mt. Auburn Hospital hematologist, had made the diagnosis. I stumbled upon him by accident. Calling to schedule an appointment with the female doctor on the team, I ended up with Barry, the physician with the shortest wait for an appointment. His poor eye contact hinted at a problematic bedside manner. Consequently, I wasn't completely surprised that he ignored the tears rolling down my cheeks, when he broke the news about the cancer to me and Bob. "It could be a lot worse," he declared bluntly.

But he got it right. For eight years I remained healthy. The diagnosis, however, took a psychological toll; watching my 5-year-old son walk into kindergarten, my eyes filled

with tears as I wondered if I would live to see him cross the stage to receive his high school diploma. Then, I would force myself back to a happier outcome. “Remember Anna’s father who stayed healthy well into his 70s with the same diagnosis,” I would firmly remind myself, “You can be like that too.”

I frequently repeated these words, my personal mantra, until 2001. That year I developed lymphoma. Thinking I had the flu, I had delayed seeing Dr. Barry until my throat felt like it was lined with broken glass each time I swallowed and the lymph nodes in my neck were as big as golf balls. A Mt. Auburn surgeon did the biopsy, but it took two long days to get the results.

Finally, Dr. Barry called to tell me that I had the type of lymphoma that responds to treatment. “Not the aggressive kind that will kill you quickly,” he added in his awkward way of being reassuring. After three months of chemotherapy, I lost so much weight that I looked like a survivor of a POW camp. But as Dr. Barry predicted, the lymphoma went into remission.

Once my physical health returned, however, I noticed a new anxiety permeating my daily activities. A trip to a crowded supermarket, pleasurable before I got sick, now made my heart race. Sitting in a hot car in a traffic jam, I couldn’t seem to get enough air into my lungs. Fears of a relapse swirled in my brain. Conversations with friends inevitably turned to lymphoma. Again, my friend Anna told me what I wanted to hear; her neighbor, a woman now in her 70s, made a full recovery from lymphoma and never had a recurrence.

For the next six years, I frequently thought about this neighbor’s good health and reminded myself that my prognosis could be like hers.

Then I relapsed.

Since my last illness Rituxan, a new “smart” drug, had improved the treatment of lymphoma. Unlike a chemotherapy that killed good and bad cells, this medication attached itself to a particular kind of white blood cell, enabling the body’s immune system to destroy these cells on its own. With three months of Rituxan combined with an older chemotherapy, the lymphoma went into remission.

Once I was well, I found a new mantra. “With Rituxan I know I won’t get sick again,” I thought.

But it is a year later, and I am wondering if I have lymphoma. With my stomach twisted into a tight knot, I dial Dr. Barry.

“You know how weird he is on the phone,” his nurse whispers, “Just come right over.”

An hour later, he ushers me into his office. He feels my lymph nodes, and I carefully study his face, hoping for a reassuring smile. But his mouth is set in a straight line. Then he turns to his computer to get the lab test results. He frowns. “You only have 500 white blood cells. The normal range is 4,500-10,000. You need to be admitted to the hospital.”

An aide materializes from nowhere, helps me into the wheel chair, and whisks me up to a hospital room on the eighth floor of Mt. Auburn Hospital, the oncology unit. I crawl into bed. A nurse jabs the IV antibiotic into my arm.

By the next morning I feel better, but my white blood count remains dangerously low. So I sit up in the hospital bed and look around the room, noticing the bland beige walls and a TV bolted to the ceiling. When I take a deep breath a vaguely antiseptic odor drifts up my nose. Then I glance out the window: a perfect view of the Charles River stares back at me. Too worried about my health to enjoy it, I lie down and try to sleep.

Just as I nod off, a man with a stethoscope draped around his neck walks into my room and introduces himself as Dr. Jones, the infectious diseases specialist. He examines me and says that he suspects that my recent course of Rituxan might have caused the dip in my white count.

But late in the afternoon, Dr. Barry appears in the hospital room and tells me that he disagrees with the infectious diseases doctor.

“I don’t think it’s Rituxan. Maybe you have some kind of virus,” Dr. Barry declares, “Let’s wait a few days and see if your white count bounces back on its own.”

I look out the window at the Charles and see the sky start to grow dark. The infectious disease doctor blames the cancer drug, and the cancer doctor suspects that a possible infection has caused the white blood count to fall.

A grim thought snakes into my brain and sucks the air out of my lungs: neither doctor knows what is going on.

Saturday afternoon, the covering oncologist, strides into my room. He recommends that I get a shot of Neulasta, the drug that stimulates white blood cell production, to bring up my counts.

But on Monday morning, Dr. Barry tells me that I can’t have Neulasta because he wants to determine the cause of the problem. I need to have a bone marrow biopsy.

“What are you looking for,” I ask as sour taste makes its way up my throat.

He informs me that he needs to rule out Acute Lymphatic Leukemia. Neither of us says anything. I look at his face, and he stares at the floor. I know that adults with this disease have a poor prognosis. When I take a second look at my doctor, he seems to be quickly retreating toward the door.

The next twenty-four hours drag by. I lie in the hospital bed, looking at the TV to distract myself. I watch soap opera characters fall in and out of love and game show contestants vie for money that could change their lives forever. Clicking back and forth, I have only one thought in my head: all these people look *so* healthy.

The inevitable “why me” question hijacks my brain. When the sympathetic hospital social worker comes into my room to ask how I feel, I spit out a biting, sarcastic “fine.” She quietly backs into the hallway.

I phone my husband to tell him about this possible diagnosis. When he tries to comfort me, I feel a terror welling up inside me that constricts my throat and makes me gag. I quickly hang up the phone.

A somber film unspools in my mind. I imagine growing increasingly weak as the end draws near. I see my husband and teenage son crying by my bedside. As the movie reaches its inevitable, sorrowful conclusion, I wonder if it will hurt to die.

Lying in that hospital bed, I feel increasingly detached from everyone. The day before I was hospitalized, my 16-year-old son and I had been enthusiastically investigating different universities at a college fair. Now I don’t care which school he goes to nor am I interested in how my poor husband will pay for college on his own.

I am only concerned about myself.

Finally, I can feel myself inching toward a “resolution.” Trapped by an impending sense of doom, I give up hope of recovery and acknowledge the likelihood that I have a terminal illness. By expecting the worst, at least I can feel that I “know” what is going to happen.

Tuesday morning Dr. Barry comes into my hospital room and inserts a needle into my hip bone to collect the bone marrow for the lab. When he is done, he hands me a tissue so that I can wipe the tears away from my eyes.

On Wednesday Dr. Barry returns smiling. I don’t have Acute Leukemia. My friend Anna sits next to my hospital bed when the doctor gives me the news. “Isn’t that good?” she says quizzically looking at the deep lines crisscrossing my forehead. “Of course it is,” I

nod to her. I try to grin but discover that my mouth feels frozen in lopsided grimace; I have prepared myself to die, and now I am scared to believe that I will get better.

My doctor lets me leave the hospital on Thursday. Since my white blood count remains low, he tells me to come to his office daily. At each visit, the nurse draws my blood. Then I sit in his office aimlessly flipping through a magazine as I wait for the results.

“No change,” he tells me every time frowning.

Disappointed, I trudge to the elevator and stumble out of the hospital’s front door. On a Friday after my appointment, I cross the road and walk on the path that borders the Charles River. The previous night’s rain left the earth smelling sweet; the small buds on the trees seem poised to burst into pink flowers. Two weeks ago, my husband and I had walked the same route, feeling excited about the arrival of spring. Now I feel numb.

During the next few days, I start to pop anti-anxiety medication to quell the churning inside me. Finally, Dr. Barry decides to try Neulasta. I sit in his office a few days later, waiting for the blood test results, afraid to hope for good news. He turns to his computer and, smiling broadly, he tells me that my counts are normal. Looking at my doctor’s face, I suspect that he is happy enough to give me a big hug, as he will do, six years from now when I thank him for keeping me alive to see my son graduate college.

I ask him about the cause of the health crisis, and he shrugs his shoulders. He looks me in the eye and says, “Maybe it was the Rituxan. We will never know for sure. Everyone, including doctors, has to live with uncertainty.”

As soon as I get better, I discover that I can finally get some air deep in my lungs. But in the months that follow, I can’t find a new mantra to keep myself calm. Finally, I give up. I decide to acknowledge the possibility of death, rather than ignore it. Then I recall my son’s birthday card that sums up my new view. “Don’t take life so seriously. No one gets out alive anyway.”

Still, it takes a while to get used to this new awareness of death; I often feel like a circus performer precariously balanced on a high wire strung between this life and whatever comes next.

Occasionally, I feel sad that my episodes of illness have left me contemplating death during so many years of my life. And, I will always envy people their good health and the luxury of time that, at least in my mind, stretches out like a long red carpet in front of them.

But then I force myself back to that silver lining. The African dance classes I took in my 50s. So what if I have two left feet. Those elaborate recipes for dinner parties with loving friends. It’s just a fallen soufflé. Embarrassment and failure, among so many other

previously troubling feelings, shrink down to size when I think about how limited my time on this planet might be.

Back in 2008 when I get well, my husband and I return to our Sunday walks along the Charles River. Parking is tight in Cambridge, and we usually end up squeezing into a space in front of Mt Auburn Hospital. Sometimes my stomach feels queasy, and I am tempted to turn away from this medical institution. But I force myself to take a long, hard look at the eighth floor, the oncology unit, as I remind myself “no one gets out alive anyway.”

Then Bob grabs my hand, and we dash across Memorial Drive to the Charles. We stroll along the path, talk about a new restaurant we want to try, and watch the river flow down to the sea.

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