

Be Lucky

Category: Stories

written by Kenneth Zeitler | November 29, 2013

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In 1996, visiting a mall during an out-of-town trip, I suddenly felt dizzy while descending on the escalator. The sensation rapidly resolved, but to be on the safe side, I went to a local emergency room. My evaluation included a CT scan of my head; the results, I was told, were “normal.”

Shortly after returning home I received another call. The CT results were not normal, and I should see a neurologist to have an MRI scan.

I panicked, as anyone would, but I had more reason than most: I’m a medical oncologist. I knew the implications of this news, and they were mostly quite dire.

The MRI revealed a brain tumor, likely “low grade.” I found this a bit reassuring—but still, it was a tumor in my head! And its specific nature was unclear.

I felt tremendous sadness and fear for my family and for all that I would miss. I was only forty-six. My son was to enter Northwestern University in the fall, and my daughter was a junior in high school; their lives were just beginning. My wife would be a young widow.

After consulting with my physicians, I decided on watchful waiting, with monthly MRIs to check for changes, and surgery as an option if needed.

Although it was my own choice, those monthly MRIs were fraught with anxiety—a sense of waiting for the other shoe to drop, with brain surgery looming at some indeterminate point in the future.

Another affliction emerged: my “dizzy spell” was diagnosed as a seizure, so now I had epilepsy too.

My doctors started me on anticonvulsant drugs. When the first two caused skin rashes, they prescribed others, in various doses. These controlled the seizures only partially, and they caused many side effects, including severe double vision and vertigo.

Although my seizures didn’t take over my whole body—they were characterized by uncontrollable jerking in my left shoulder for one or two minutes—they were frequent, unpredictable and embarrassing. Luckily, there was always some warning beforehand: I sat by the door during patient consultations or other gatherings, so that I could escape in time to seize in privacy.

Eight months later, the scan revealed changes in my tumor. Now I needed surgery.

The tumor was located close to the motor area of my brain. Concerned about preserving my mobility, the surgeons needed me to stay alert and able to move my limbs upon request, so they recommended “awake” surgery.

The idea of being awake during neurosurgery was frightening, to say the least. Still, given the alternatives, I had no choice but to steel myself and trust my surgeons, who were also my colleagues.

During the procedure, I could hear all their discussions. These were very scary; it may have been the effect of the anesthesia, but I seem to remember, at one point, their talking about some problem with a battery that was powering the equipment.

My one wish, going into the surgery, was that I would emerge with at least some cause for hope. My wish was granted. The tumor was a low-grade malignancy (grade II oligodendroglioma) with some favorable features. When I ran to my textbooks and the internet for details about oligodendroglioma, though, I encountered a disheartening prognosis: an average life expectancy of just four years, with recurrence virtually certain.

The following ten years were marked by watchful waiting and frequent MRIs, each one laden with anxiety. Just when I began to believe that I had been spared, my MRI again showed tumor progression.

My local neurosurgeon suggested that I consult with a range of authorities—a neurosurgeon, a neuro-oncologist and a radiotherapist—but cautioned, “You’ll get as many different opinions as there are specialists.”

He was right. The famous surgeon suggested more surgery, the renowned radiotherapist recommended radiation, and the eminent neuro-oncologist recommended chemotherapy.

Another colleague suggested a fourth option, continued observation. After carefully consideration, I chose this.

In retrospect, it was the right choice. It has allowed me to see my son and daughter graduate in turn from college and medical school, then marry; my son and his wife now have two children, and my daughter is expecting. My wife and I have grown even closer. I have continued to enjoy work, travel, bicycling and friendships.

Still, I know this choice was made possible only by my good fortune in possessing medical training, with its attendant research skills and clinical intuition. I can’t imagine how anyone without that training could possibly make sense of all those conflicting medical opinions.

I have far exceeded the expected prognosis. Only now, almost twenty years after my initial diagnosis, have I finally relapsed.

A brain biopsy confirmed that the tumor has become more aggressive. This bad news was compounded by complications during the biopsy: bleeding led to emergency surgery, leaving my left side paralyzed.

I feared that my precious independence was gone forever, but with excellent rehab and a lot of hard work over the ensuing four months, the paralysis has mostly resolved. I can once more dress, shower, drive and do the many other things that we so often take for granted. I've returned to work at the hospital where I practiced for thirty-five years.

And, of course, I have my family.

There is much to be grateful for.

I have begun radiation and chemotherapy and so far have managed to avoid any complications. Statistically, my prognosis is quite poor; but the bell curve of survival has a tail on it—a tail signifying the small minority of patients who significantly surpass the norm. However slim this chance, it allows me some hope, to which I will cling as long as I possibly can.

Looking back at my illness, I know that I've gleaned many lessons: seek the best counsel available, but also do your own research; trust your instincts but do not follow them blindly; be hopeful when that is an option.

And, perhaps most of all—be lucky.

About the author:

Kenneth Zeitler practiced medical oncology/hematology for thirty-five years at Rex Hospital in Raleigh, NC. He is now a development officer at the hospital and volunteers at a free medical clinic. His interest in writing stems from his college studies as an English major. Other interests include travel, documentary studies, Carolina Hurricanes hockey, college basketball, photography, hiking and his grandchildren. "I have been married since 1975 to my wife, Joyce, who is a psychiatric social worker. I am her best patient, considering what she had to start with for raw material."

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