

# Reflections

## **Bergen-Belsen, metastasis and dancing with the devil**

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**F**or close to 35 years, I have studied and cared for people with cancer—carcinogenesis, mutations, clonal evolution, angiogenesis, metastasis, chemotherapy, immunotherapy, signal transduction inhibitors. I am not sure if a scientific understanding of cancer makes it easier to live with; probably not. In some regards, it is like dancing with the devil. The key is that you always want to lead when in this dance.

Many friends and colleagues were shocked when I diagnosed my own cancer. Most were extremely supportive as I went through my treatment ordeal. I don't care for the term journey when describing cancer because in my mind that suggests something desirable or pleasant, and it is anything but that. The antithesis of a journey. The surgery hurts like hell. "Hand-assisted laparoscopic nephrectomy" is medical jargon for having your kidney ripped from your body.

I had a lot of visitors when I was hospitalized. That part was actually really nice and people were very kind. Cards, books, chocolate and more edible fruit arrangements than I could ever imagine! Who knew pineapple could be cut into so many shapes? My family was awesome, and my patients were unbelievably supportive.

Unfortunately, a few acquaintances had comments that forever earned them a place in the schmuck hall of fame, such as, "now you know how your patients feel," and "everything happens for a reason." These comments are neither insightful nor helpful. Cancer is caused by a mutation, not a spiritual message.

To this day, a very sick feeling comes over me when I pass by my old hospital room. I imagine it is a form of PTSD, and I try to avoid that floor.

During my recovery, I found myself gravitating to my closest patients, friends, and colleagues who had dealt with cancer themselves. It was almost like joining a secret society, a club nobody wants to join, but some are forced into through no fault of their own. There is a look cancer patients give each other in recognition of their shared misery. When we pass each other in the hallway, we give one another that look, a wink without winking, which says, "I get it."

Kidney cancer, like other types, is classified by stage. Stage I is small and localized, Stage II is larger but still contained, and Stage III implies that some of the malignant cells have started to migrate. I had Stage III (T3a) meaning there were cancer cells in the renal vein before it exited the kidney; beginning their journey downstream, yet still all contained within the kidney. That put me at risk for recurrence as some cells, on a microscopic level, may have already escaped. Which leads me to one of the most fundamental questions about the nature of cancer—do cancer cells swim or crawl? Scientists have studied this for decades.

No matter what I am doing- in the shower, taking a walk, listening to music— I find myself focusing on that swim or crawl question. Do the cancer cells slowly march down the renal vein like little penguins, or do they get into the bloodstream and swim away? Did my doctors "catch" them before they marched too far?

Many years ago, I worked in a research lab studying the behavior of leukemia cells, trying to get insight into similar fundamental questions. If cancer cells crawl most of the time, I may be okay. If they swim, they may have already implanted somewhere. They could be lying dormant waiting to reactivate, or pounce, in my lungs

or bones, or worse yet, my brain. It would be horrible beyond words if my brain was someday held captive by those damn cells! Would it impact my knowledge? My sense of humor? My memory? My love of music? My love of movies? My love of chocolate?

The literature states, about 15 percent to 20 percent of people who have T3a kidney cancer will relapse at some time, developing metastatic kidney cancer.

I researched if the recurrence rate differed between left and right sided kidney cancer. Perhaps it was wishful thinking, but my thinking was since the renal vein is longer on the left (my side), the margin between healthy tissue and cancer would be larger. Unfortunately, I couldn't find any data supporting that hypothesis. There is data about the grade of the tumor. And, there is data about the destructiveness of the tumor, i.e., the necrosis.

My cancer is pretty good regarding destructiveness, and not too bad on grade. At this time all I can do is wait and keep my fingers crossed. If I was inclined to pray, I would. I don't mind when good natured friends, family, and particularly patients say they are praying for me. It is a very kind expression of support and love. Something we could certainly all use more of.

I was pretty health conscious at baseline so that hasn't changed. I drink green tea, I eat natural black licorice, I eat ginger, I put turmeric on my food, and I take Astragalus purchased from the health food store. All natural agents that are either anti-oxidants, anti-angiogenesis factors, or immune activators of some sort. Nature may have some helpful substances out there, hopefully my T cells are listening.

When I am in settings or gatherings where they ask cancer survivors to stand up, I don't. I am not embarrassed or ashamed, I just don't want to stand up. I will discuss it with people if and when it seems comfortable to have a very personal conversation.

I have known many cancer survivors, and a variety of other types of survivors. The survivor term is used for many groups of people—Holocaust survivors, cancer survivors, survivors of abuse/violence. All extremely worthy of support and compassion.

I know from spending considerable time with Holocaust survivors, there is a hierarchy of sorts, similar with cancer. Having a small skin cancer with no risk of spreading is like getting out of Germany before Kristallnacht in 1938. You have some sense and understanding of the fear, but you are ultimately fine.

Surviving Treblinka or Sobibor, on the other hand, is like surviving the most aggressive malignancy where

essentially no one is expected to recover. But a few lucky souls did survive those extermination camps, and some cancer patients with the most horrible cancers, sometimes survive.

Holocaust survivors often say it was luck that enabled them to survive. Perhaps it is the same with some cancers. Where do I fall on this cancer/Holocaust scale? It is hard to know but I'm thinking (and hoping) that I am like a person who is captured in occupied Europe in 1939, rounded up and placed in one of the Polish ghettos, but escaped before the 1942 deportations to Auschwitz started.

In October 2017, I attended a celebration on the one year anniversary of my friend Henry's death. Henry and I were on the same remembrance march to eastern Europe and Holocaust sites in 2014. Henry was a truly remarkable Holocaust survivor, and since I was the physician on the trip, I was asked to help him as we visited more than a dozen historic and emotionally overwhelming sites. That trip was truly one of the most meaningful experiences of my life. A speaker at Henry's memorial ceremony made the cancer/Holocaust analogy.

Starting at age 12, Henry was transported first to Terezin and subsequently to Auschwitz, then Dora-Mittelbau. Ultimately, he was liberated from Bergen-Belsen in April 1945, on his 15th birthday. He was at Bergen-Belsen at the same time as Anne Frank. They were the same age.

Henry's life was quite astounding—like a cancer patient with an aggressive malignancy and multiple relapses who remarkably enjoys life for 70 more years after enduring horrendous treatments. Maybe cancer survivors ultimately are liberated too. Although cancer survivors don't have a tattoo on their arm, like the Holocaust survivors, we have a tattoo on our souls.

My cancer has continued to weigh on me. Just hoping to always lead as I continue to dance with the devil.

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