

An Odyssey of Hope

by Meg Gaines

I appreciate the opportunity to speak to oncologists the world over, although with a stringent word limit. This perhaps is the definition of frustration for a lawyer who has survived cancer. Nevertheless, I know better than to sacrifice an opportunity at the altar of perfection.

First, my "credentials." At age 38, I was diagnosed with a "small focus of clear cell carcinoma" within what was said to be a "borderline tumor" of my ovary. Eight months later, after blood clots were developing at random (including in my lungs), 3 lesions were discovered in my liver, including 1 that was biopsied and measured 8 cm. After my left lung was punctured while a Groshong catheter was being installed, and a second (larger) chest tube at last reinflated it, I was treated with paclitaxel and cisplatin. However, this "gold standard" was not effective against my tumors and I was scheduled for surgery.

For some reason I insisted on a portogram before my surgery. The surgeon entered my room with a grim face and told me that there were 12 visible lesions in all 3 lobes of the liver. My children were ages 1 and 3 years at that time. I remember his face; he was a young man, probably around my age, who had young children of his own. He clearly was sad and he obviously felt helpless; he even offered to talk with my children when, in the midst of tears, I asked what I should tell them myself. Before he left my room, he said with authentic compassion, "Go home and think about the quality, not the quantity, of your remaining days."

I did go home, but I did not think about the quality of my remaining days. I made appointments at 5 hospitals in 4 cities and 5 weeks later found myself undergoing cryosurgery at a hospital in a city far from where I live, where it was discovered that there was and had been only 1 lesion in my liver. The other lesions were cysts and irregularities of blood density that are common in approximately 10% of the population. That was in March of 1995. This year, my gynecologic oncologist dubbed me a "durable survivor."

Had I gone home, given up hope, and lived out my remaining days, I doubtless would have died (although quite a bit later than expected) with loved ones remarking on what a testament my surviving longer than predicted was to my will to live. I attribute my survival to several things. First, I am an educated woman with a privileged upbringing who does not easily take no for an answer, particularly when it involves my own mortality. I have the emotional and financial resources to know that no professional- (physician, lawyer, or engineer) knows all there is to know about a given problem and the more intelligent individuals you have involved,

the better off you are. So, I held the doors open when they appeared to be closing on me. Second, and just as important, I attribute my survival to several physicians who were willing to risk their professional reputations and my life, and take chances others would not. They were willing to have hope when hope was in short supply.

When I was diagnosed with cancer, it was as though I found myself in a boat in a tempest. The wind blew hard and the waves sometimes were enormous. I would not survive alone, of course; there were many others in the boat with me: family, friends, physicians, nurses, and several oncologists. Often I was the captain, I had the tiller, and was the one best able to steer. And sometimes the best I could do was tremble down below because the waves were too terrifying for me to watch. Many times, a particular wave was better handled by someone else and I stepped aside and simply took an oar. For a patient with cancer, the ability to step aside and trust someone with your life is as crucial as the ability to select carefully who that person will be.

We are not the ocean or the storm; neither patient nor physician can control the outcome. Although I have been free of cancer for 5 years, I remain acutely aware that I may very well die of cancer at some point. I do not imagine that I have control of that monster. But I do not have to give up control, because I never had it. Control is an illusion that we preserve to manage the randomness and chaos of life and death. What we must let go of, then, simply is an illusion.

Patients with cancer do not need false hope, but neither do we need false and fatal abandonment of hope. We need to be brave enough to have real hope, and our physicians must too. Real hope is born when we let go of the illusion of control over the outcome without truly giving up. Real hope is staying invested in the outcome even as we know we cannot control it. Sometimes we are able to have an influence that changes the outcome, but that can happen only if we are willing to remain in the process even though we may die.

Each survivor has a story, an odyssey of survival. And every one of those stories tells of people along the way, each one a link in the chain of survival. You are presented almost daily with the opportunity to join someone's chain. But remember this: you cannot be the whole chain; you must not take on that impossible task. If you are willing to take thoughtful risks you have the opportunity to be a critical link in many chains. You save lives every day. Or you do not. When it is your turn to take the tiller, when you are most capable of guiding the boat through the next wave, take it and do the very best you can. It has been my experience as a lawyer and as an advocate for patients that as long as I communicate and make it clear that I am doing the best I can, my clients and their families are grateful. No one can ask more of us, and we must never give less.