

12-10-2009

Salvaging, Surrendering, and Saying Goodbye to My Leg

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Recommended Citation

Ellingson, L. L. (2009). Salvaging, Surrendering, and Saying Goodbye to My Leg. *Health Communication*, 24(8), 773–774.
<https://doi.org/10.1080/10410230903318497>

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Nearly twenty years after my diagnosis with osteogenic sarcoma – a virulent, fist-sized tumor in my right femur just above the knee – my surgeon and I made the difficult decision to amputate my leg. After twelve reconstructive surgeries on my leg (and several on my chest and abdomen), thirteen months of chemotherapy, three major staph and/or strep infections in my knee, and a promise that yet another surgical reconstruction of my leg would necessitate a lifetime on daily antibiotics and give me a knee that would almost certainly cease to function within a couple years, I was done.

I had a good cry, talked with my spouse Glenn, and then called and left a message with my surgeon's nurse. "Please tell Dr. Leightonⁱ I'll take the amputation," I told her.

How did I end up here? Did my surgeons or other physicians do something wrong? Did I? I do not believe so. Medicine is an imperfect art and a continuous experiment in science. It comes with no guarantees – not that I would believe one if it were offered. Our collaborative artwork and experiments have kept me alive and reasonably functioning for 20 years, and I am grateful. Over the years, as I grew older and had more experience with the health care system, I moved from believing that if I just did what my physicians told me to do then everything would be all right, through disillusionment and skepticism, and finally into a partnership role in which I discussed options with my physicians, and we made decisions jointly. To be sure, I was an unusual case, and no one could predict with a high degree of certainty how my body would respond to the continual "revisions" of my leg. Each of my surgeons had done excellent work, and it still hadn't permanently fixed the problem. While I was disappointed in the outcome, I took an equal share of the responsibility for the decision making. And when I declined to continue our limb-salvaging experiments, I was grateful that my inclination to change directions was met with respect and cooperation.

“I could rebuild it one more time, if you wanted,” said Dr. Leighton gently. “I won’t give up until you’re ready.”

“No,” I said. “Thank you for all you have done for me. But I’m done now.” He nodded with a small, sad smile. It was the end of an era, the end of our questing and scheming and strategizing. Most especially, it was the end of two decades of hoping for a permanent fix. Dr. Leighton was close colleagues with my two previous surgeons and over the years had kept them updated when he saw them at conferences, sharing our ongoing saga.

I was done with limb-salvaging, but I did not feel done with my leg. I was very attached to it; we’d been through a lot together.

“What will you do with my leg after the amputation? I mean, where does it go?” I asked Dr. Leighton.

He shrugged. “We just throw it out with all the other gallbladders and appendix we took out that day.”

“What if I want it back?” He looked at me blankly. “I mean, if I want to get it cremated so I can have the ashes?”

“I’ve never looked into that,” he said. “But I’m sure it’s fine if you want to.”

“Don’t most patients request that their limbs be cremated?” I asked incredulously. Dr. Leighton just shook his head. Overwhelmed with a combination of grief for my impending loss and relief that it would be my last leg surgery, I couldn’t explain why I needed to have my limb’s ashes returned to me. I simply knew it was something that needed to be done.

Thus began my journey to get my leg back. While Dr. Leighton was very supportive, he didn’t know to whom I should speak in order to make arrangements.

Over the next two weeks, I talked to representatives from the hospital's Patient Services Office, a nurse, and the receptionist in the sarcoma program. All of them responded with a variation of, "Oh. I don't know. No one has ever asked me about that. I'll have someone call you back."

After I found out from Dr. Leighton that they would be testing the limb before disposal, I contacted the pathology department directly using a number I found on the hospital's website. I left a message and a friendly woman named Eileen returned my call. She also didn't know how to help me, but she assured me it was indeed possible to have a body part cremated and promised that she or another staff member from the pathology department would get back to me. Eileen made arrangements for the pathologist to release my leg following postsurgical testing, and gathered the necessary forms for me to sign in order to authorize the release to a licensed funeral service (strict laws govern the release and disposal of body parts).

I then began calling local cremation services, opening the conversations with what was certainly one of the strangest questions I had ever voiced. "Hi! My name is Laura Ellingson. I am about to have my leg amputated, and I was wondering if you cremate individual body parts, and if so, how much that would cost?"

The response from the soft-spoken woman at the cremation service was eerily familiar: "I am sure we can help you, but I don't know how it would work. I'll have someone call you back."

I heard soon after that from a sales associate who matter-of-factly quoted me prices for the pick up, cremation, and delivery services. I gave him a credit card number, signed more paperwork, and was assured that the company would pick up the limb as soon as it was ready. When I signed paperwork at the pathology department the morning of my surgery, I asked if they would notify the cremation service when my limb was ready. They wouldn't but gave me a

number to call so that I could check on its status myself, suggesting the process would probably take a couple of weeks. I called the pathology department after returning home from the hospital, then informed the cremation service.

About two weeks later I received in the mail a box with a plain brown wrapper containing my leg ashes. I put this symbol of my collaborative medical decision making into my closet, and ignored it for a year. The amputation was done, and I was more than ready to move on. I turned my attention to the frustrating process of learning to walk on a C-leg prosthesis that sported a computerized knee joint. For inspiration, I named the prosthesis after indefatigable suffragist Elizabeth Cady Stanton, and Cady and I did exercises and gait training for months.

On the anniversary of my amputation, Glenn and I went out for a wonderful dinner at our favorite restaurant in a lovely spot in coastal Maine. Afterward, full of seafood and Death by Chocolate cake, we drove down to one of the local docks. I walked with the aid of Cady and a cane down to the end of the dock and surreptitiously but joyfully dumped my leg ashes into the ocean.

“How do you feel?” asked Glenn, holding my hand in his much warmer one.

“Good,” I answered. I thought for a moment and sighed. “I’m done.”

Endnote

- i. All names have been changed to protect health care providers' privacy.