

The Survivor and the Pea

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WRITER'S COMMENT: When Dr. Mardena Creek introduced the assignment to write a case study for UWP 104F: Writing in the Health Professions, I instantly had an individual in mind. Breast cancer has become a topic incredibly close to heart since my mother's diagnosis with a hereditary form of the disease in 2008, and this assignment presented a perfect opportunity to delve closer into her experience. Interviewing her allowed me to synthesize the chain of events related to her diagnosis, treatment, and recovery that had taken place throughout the previous two years. During the writing process I came to better understand how the intersection between an individual's personal disease experiences and the difficulties of navigating the health care industry presents unique challenges for patients. I would like to thank Dr. Creek for her support and guidance, as well as my mom for serving as an undeniable pillar of strength.

—Kyle Ryan

INSTRUCTOR'S COMMENT: A triathlete since age eight, Kyle Ryan thrives on challenges, bringing the same focus, discipline and passion to his writing as he exhibits when participating in his sport. Kyle wrote this engaging paper in response to a standard assignment in UWP 104F (Writing in the Health Professions): a case study of a medical condition directed to a lay audience. Popularized by physician/writers such as Oliver Sacks and Atul Gawande, this type of case study not only educates readers about a medical condition but also explores its human implications. Based on an interview with his mother, a fellow triathlete and breast cancer survivor, Kyle's case study presents an inspiring story of one woman's response to a devastating diagnosis. Skillfully integrating medical information gleaned from his research on breast cancer into the flow of a narrative spiced with pithy quotations and telling details, Kyle's case study is a model of the genre, providing both information about a disease that will affect over 12 percent of women born today and insights into its emotional ramifications.

—Mardena Creek, University Writing Program

DURING EXERCISE, NOTICING THE DIFFERENCE between muscle fatigue, pain, and injury can sometimes be incredibly difficult. A sharp pain in the side could be merely a muscle cramp but could also signify something more serious like a torn muscle or broken rib. For Diane, however, years of sport have blessed her with a fine-tuned ability to recognize her body's warning signs. "One day in August of 2008," says Diane, "every time I did a flip-turn during swim practice I felt something funny in my right breast. At that moment I knew I had breast cancer."

Based on her appearance, Diane, a fifty-one-year-old homemaker and mother of two who stands five feet tall, has clearly been an athlete for most of her life. Diane was a gymnast in high school and in college, started running after she married in her early twenties, and took up triathlons at the age of thirty-five. An avid triathlete for over fifteen years now, she balances swimming, biking, and running with maintaining her home, spending time with family and friends, and walking and running Bella, her year-old chocolate Labrador retriever, twice a day. While swimming, biking, and running for over fifteen hours a week may seem unimaginable to most mortals, Diane embraces the time she spends pushing her athletic boundaries. She attributes her drive to train for triathlon events to her desire to maintain a healthy lifestyle: "I always thought that one day I might get cancer," says Diane. "I've done everything that I could to prevent it—eating right, exercising, not smoking. My family history finally caught up with me."

Cancer runs deep in Diane's family. "My grandmother died of ovarian cancer in her forties," says Diane. "My mom had skin cancer in her late thirties, breast and bladder cancer in her forties, and lung cancer when she passed away at seventy-six. My brother Craig had skin cancer, and my other brother Kevin had brain cancer. Many of my female cousins had breast cancer and pressed me to undergo genetic testing for the BRCA gene over fifteen years ago." Today, genetic testing can reveal if someone has genetic mutations, or changes, in certain parts of their genetic makeup. Mutations in certain genes like BRCA1 and BRCA2 put a woman at greater risk for developing breast and ovarian cancer in the course of her lifetime (National Cancer Institute 2009). Two of Diane's cousins tested positive for mutations in the BRCA gene in the 1990s and underwent prophylactic mastectomies, a precautionary removal of one or both breasts to prevent the development of cancer. "My cousins

wanted me to get tested in my thirties, but I didn't want a prophylactic mastectomy—I was busy raising my family," recalls Diane. After the funny feeling hit her in the swimming pool twenty years later, she made an appointment with her obstetrician for the following day.

According to the National Cancer Institute, there are not usually any symptoms of early breast cancer. Most women contact their doctors when they recognize a lump or thickening near the breast, a change in breast size or shape, or an inward turning of a nipple (National Cancer Institute 2009). Diane, however, did not have any of these symptoms. Luckily, she has a close relationship with her obstetrician, who agreed to Diane's request for a digital mammogram, or X-ray picture of the tissue inside the breast. Doctors commonly use digital mammograms for diagnostic purposes after a sign of a tumor has already manifested, but Diane intuitively knew to ask for one. "I remember after I had the digital mammogram," recalls Diane, "they asked me, 'Can we do an ultrasound?' I replied, 'Oh, of my right breast?' And they said, 'Yes, how would you know that?' I responded, 'Well, because there's something wrong with it!'" The doctors found a four-millimeter tumor—almost half the size of an average pea—but they assured her that there was almost no possibility that it was cancerous. To confirm, the doctors performed an ultrasound guided core needle biopsy, using a large hollow needle guided by ultrasound imaging to collect a sample of breast tissue (National Cancer Institute 2009). Diane waited anxiously over a holiday weekend for the results and received a call on the following Tuesday to come into the doctor's office to learn the news. "I felt so sorry for the radiologist," she recalls. "He said, 'I have to tell you that you were right. It is cancer.' He felt so bad and looked like he was going to cry, even though I had known it all along. I remember trying to make him feel better, which was kind of odd since I was the one who had just been diagnosed with cancer." Diane emanates strength. While her body is sculpted from exercise, her mind and determination are fortified by her life experiences. She retells the events of her diagnosis and treatment almost nonchalantly, which nearly makes me forget the hurdles that she has overcome in the past year and a half.

"Don't get me wrong," Diane admonishes. "I was scared to death. I'm scared of even having a blood test. Before this I had never had a major surgery. I was petrified, full of anxiety, was scared of the unknown, had fear of dying on the operating table. I imagined having giant scars

like my mom had after she had her breast removed.” Large scars have become less of an issue over the years with today’s surgical technology, but the importance of finding a caring and understanding physician has not. Though the tumor was only four millimeters in size, it was a Grade 9 tumor, the most aggressive form possible. Diane immediately began searching for a surgeon to perform the operation. Even though the first breast surgeon Diane visited was renowned for his work, she was unsatisfied, and even offended, by his comments. “He told me to my face,” she stresses, “that there is no way that I could have found the tumor because it was too small. He asked me, ‘What are you, the princess and the pea?’” referring to a princess from a Danish fairy tale who cannot sleep because she feels a pea beneath twenty mattresses and twenty featherbeds. The surgeon suggested that she have a lumpectomy with radiation, in which the cancerous tissue alone is removed and the surrounding area radiated, and that she have the procedure soon.

Remembering her family’s cancer history and her cousins’ positive tests for the mutated BRCA gene, Diane became concerned about the possibility of also carrying the mutation. She knew of studies indicating that patients who carry the BRCA gene mutation and receive a lumpectomy, as suggested by the first doctor, have a 40 percent chance of developing cancer in the other breast within ten years (Metcalf et al. 2004). With an important triathlon fast approaching, Diane declined the doctor’s suggestion and instead visited an oncologist to ask about genetic testing. Before proceeding with any surgery, she decided to have the testing, enjoy her triathlon, and make her decision later. “I tried to be as normal as possible during the weekend triathlon trip with my family, but I was scared,” says Diane. She placed in the top three women in her age group at the race, and finished hand in hand with one of her best friends, with whom she had just shared the news.

According to the National Institutes of Health, 12.7 percent of women born today will be diagnosed with breast cancer in their lives (Ries, et al. 2006). Following skin cancer, breast cancer is the most commonly diagnosed cancer among United States women, though only 5–10% of all breast cancers are estimated to be caused by genetic mutations. For the subset of patients who carry such mutations, however, the risk of contracting cancer increases significantly; women with mutations in the BRCA1 and BRCA2 genes have up to an 80% risk of developing breast cancer at some point in their lives (“Breast Cancer Statistics”

2010). When Diane found out that she tested positive for a BRCA1 gene mutation, she remembers being relatively unsurprised and more determined than ever to go forward with a double mastectomy to surgically remove her breasts. “My husband and sons were extremely caring and concerned throughout the diagnosis and treatment,” recalls Diane, “but I didn’t really need that much support. It was already a done deal.” Diane’s bullheaded strength was more conspicuous than ever.

Diane met with four different breast surgeons and three different plastic surgeons before deciding on her team of two physicians. Though the plastic surgeon operated out-of-network, he was the only one who would perform the double mastectomy and breast reconstruction during the same surgery. Other surgeons preferred to delay reconstruction, using expanders—hard, round plastic devices that are placed under the breast muscle and injected with saline over the course of several months—to expand the surrounding tissue. Completing both procedures at once would lessen the recovery time and allow her to begin training sooner. Though Diane was diagnosed in early September, the first available opening for the breast and plastic surgeon was October fourteenth.

When I asked how her recovery went, she scoffed, remarking, “Recovery? There was no recovery from the surgery! I left the hospital the following morning and walked around the room really fast to show them I was ready to leave. I was off of pain pills within six or seven days, could walk miles by a week and a half, and was back on my indoor bike trainer within two weeks. My son had to keep his eyes out for me and stop me from vacuuming when I was supposed to be lying in bed with my arms at my side.” It is nearly miraculous that Diane intuitively discovered the tumor when it was so small. Aggressive tumors like the one found inside her breast are particularly dangerous because of the possibility of metastasis, or spreading of the cancer to different parts of the body. Many women discover that they have breast cancer at more advanced stages of the disease and must undergo chemotherapy to damage the cancer cells as much as possible. Unsurprisingly, her surgeons were amazed at her swift healing and extraordinary health. “The worst part,” Diane recalls, “was actually that my dog had died before my surgery, so I spent a lot of time alone when my husband had to return to work. Luckily, we found Bella by early November, so I had something to look forward to!”

Diane’s recovery went relatively smoothly, though she had a revision surgery in August of 2009. She found the implants the plastic surgeon

used too large, so that she hit them with her knees when riding her bicycle in the “aero position,” where her arms are laid out in parallel on special time trial handlebars. “This was a constant reminder that I had had breast cancer, and sometimes I just didn’t want to think about it,” she said. After her second surgery, Diane is now back and training in full force for triathlons. “I’m just happy to be here,” she states with a subtle smile. “When I was younger, I didn’t want to grow old. Now I’m 51 and am all for getting old! I’m still alive! Also,” Diane emphasized, “the older you are the better you get in triathlons. I want to be first *all* the time.”

In November of 2009, Diane participated in the Race for the Cure, the largest series of 5-kilometer run/fitness walks in the world, which raise money and awareness for the fight against breast cancer. Diane ran and placed second among all breast cancer survivors at the event. When she shared the news with her friend at swimming practice, the woman was congratulatory, but responded that “she would never look at Diane and consider her a survivor.” Diane recalls leaving the pool deeply offended, but later realized that her friend had good intentions. The image Diane’s strength paints seems to have transcended her friend’s imagined portrait of cancer survivors. While she still finds it somewhat uncomfortable to swim, bike, and run, the obstacles she overcame have instilled in her an even more powerful drive to surmount life’s daily battles.

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