Transformation of a Reluctant Patient to a Proactive Health Advocate

Peg Ford, Ovarian Cancer Alliance of San Diego, San Diego, CA, USA

ABSTRACT

In this article, the author explores her journey first as a person encountering the most devastating experience one can have on Planet Earth as a human being - facing a life-threatening health crisis. The other journey was even more challenging - how to live your life as a survivor with always facing the risk of a recurrence of the most lethal gynecologic cancer, and the importance of making sense of this experience. The author has learned to look at life experiences for the gifts and the lessons and this certainly is a major one.

Keywords: Cancer Survivor, Illness Narrative, Ovarian Cancer, Ovarian Cancer Alliance of San Diego, Patient Advocate, “Survivors Teaching Students”

THE BEGINNING: MY LIFE BEFORE THE “BIG C”

Prior to this life-altering event, I was an extremely healthy fifty-nine year old, independent, unmovable object of determination, grit and steel that could do everything by herself. Or, so I thought. In addition I, nor most of the female members of my family, ever trusted the medical profession. Growing up in a large struggling working class family in the 1950’s, my parents could not afford health care and for that matter, could not afford for me to be born in a hospital. I was born at home on a cold Canadian winter evening entering the world in my family’s living room as my Grandmother’s clock struck six o’clock. The doctor had recently returned home from the Second World War and I was his first delivery. My mother stated he brought a new gown but never had the chance to put it on as I obviously was anxious to enter the world quickly! As for a number of people back in those days, health care was not a consideration, and certainly not in my financially-stretched family.

My limited experiences with western medical care were neither appealing nor valued. For example, the only intrauterine device (IUD) that my body did not react to was the Dalkon Shield which they pulled off the market due to serious reported adverse events. I will always remember the doctor glancing over the sheet while my feet were in the stirrups saying, “This hurts going in (shield) and hurts coming out,” before he released the shield and I passed out from the pain. I started gravitating to alternative
healing methods for any aches and pains feeling more comfort and satisfaction which became my choice of care for most of my adult life.

This was to change when turning sixty, as I needed crisis surgical care from the medical community which would not only save my life, teach me major lessons about the world of western medicine, but altered my life’s path.

**“Make Sure He Gets It All”**: My Tryst with Cancer

Shortly after New Year in 2007, just before my 60th birthday, I was on my knees in tears. I cried out loud, “I cannot do this alone God”. I was struggling with major problems relating to my abdomen since taking quite a tumble on the sidewalk in September of the previous year. X-rays showed two hair-line fractures in my left shoulder, with my left wrist and hand badly sprained.

Shortly after, I started having vaginal spotting. I thought I had jarred my ovaries from the fall. I also started to note I was increasingly fatigued, no matter how much I rested. My abdomen continued to swell and got progressively worse over the next three months. The increased spotting and bleeding for two weeks troubled me. When groin and back pain joined the symptoms, I sensed this was not just a physical reaction to the fall, but something that needed some serious help. My initial concern quickly gave way to quiet desperation and panic. Thankfully, a dear friend pushed me firmly but gently, to go see her female gynecologist.

The very next day I underwent a transvaginal ultrasound. The gynecologist’s terrifying call spoke of a huge mass in my abdomen requiring surgery as soon as possible. Surgery! Up until age 60, the only episodes of surgery were my tonsils removed at age 23 and the tubal ligation at age 32. This gynecologist referred me to a female surgeon who, upon her examination, wanted to do surgery sooner than later. However, when she received the CA-125 report, she referred me to a highly regarded female gynecologic oncologist who happened to be out of the office for a few weeks. That same night, I had a dream where a voice said, **Make sure he gets it all**.

It would seem the Universe purposely pre-arranged this for me to accept an appointment to see her esteemed male colleague two days later. After his examination, this doctor arranged for me to enter the hospital for surgery right after the weekend. He stated, “I want you to have an EKG and abdomen CT scan tomorrow (which was coincidentally on the day of my birthday) as I want to make sure I get it all”. I knew from his voice repeating the same words I heard in my dream, this was my surgeon. He saved my life by removing a very rare sex-cord stromal tumor generally found in approximately 5% of cases and usually in young women between 20-25 years old. Decompressed, the tumor, which had enveloped my left ovary, was between 30 to 35 centimeters (Figure 1). I found a letter from the Professor of Pathology of Harvard Medical School attached to the pathology report. Apparently, my specimen had been sent to him for his opinion as his letter stated, *“This is a granulosa cell tumor; although perhaps not the most typical indeed”*. But I am getting ahead of myself.

**The Cancer Diaries: Dealing with Surgery and the Road Ahead**

The days leading up to the surgery were a living nightmare. I was scared, vulnerable and uncertain about this health crisis with no medical insurance. The sheer size of the mass concerned my surgeon from the beginning that I could very well end up in intensive care. My ears could not believe or hear clearly what he was saying. Thank heaven my friend had accompanied me to this appointment as I could not digest or retain the information coming at me.

Divorced, living on my own with no immediate family nearby I felt totally alone. The series of events resurfaced a hidden memory of helplessness at the age of six on my first day of school, when my brother opened the kindergarten door, shoved me in, and closed the door.. The intensity of the ingrained memory...
Two Case Studies in Human Factors in Healthcare: The Nurse and Older Patient
www.igi-global.com/article/two-case-studies-human-factors/53871?camid=4v1a

EONS an Online Synaptic Modeling Platform
www.igi-global.com/chapter/eons-online-synaptic-modeling-platform/12981?camid=4v1a