

A Tale of Two Diseases

The room is quiet except for the throaty and irregular breathing sounds emerging from deep inside my mother's sick lungs. Outside, a break in the thick clouds permit sunlight to sneak its way through frosted windows turning the darkness to a lighter shade of grey. Despite the cold February morning, the room is made warmer by the cumulative heat of people surrounding her bed. Soon, death will cast the room with silence, gloom and a profound chill.

A gaunt face, with sunken eyes and recessed cheeks from days of not drinking or eating, protrudes from underneath thick blankets. Neck, hyperextended and mouth, agape, she hungers for air. Deep furrows etch her forehead and thinner ones haphazardly encircle her eyes giving the appearance of roadmaps with no clear destination routes. It is easy to tell which lines were burdened more heavily from her painful grimaces of the past few days. Her hair, now thin and wispy; the soft skin, a waxy, almost pale yellow hue, adorns what is left of my dear mother.

The target of two life-robbing diseases, dementia and cancer, Mom was now unconsciously yielding to them both. Her formerly sharp mind, once full of precious memories and thought, continued to erode. Her body, previously so vibrant, withered to almost nothing. Both diseases effectively created a shell once filled with hope, dreams and love; yet, ironically, even providentially, they also worked in concert, harmonizing with each other to mercifully protect her. The dementia made her unaware of just how sick she was from the cancer. This graciously spared her from fear, anxiety, pain and worries—she had no sense of mortality. At the same time, the cancer stole her life quickly, saving her from further indignation, humiliation and frustration that dementia leaves in its insidious path of destruction.

Before the two diseases joined forces to consume her life, Mom espoused an exuberant lifestyle. She exercised when such activity wasn't fashionable; she took vitamins when people just didn't do that; she mowed her own yard, trimmed bushes and cut down trees when most women of her generation typically stayed indoors cooking or sewing. Vigorous walks in the mornings—no matter what the weather—were a lifelong habit. She occasionally indulged in fast food treats with her little Maltese dog, but most of the time she was prudent about what she ate. She was seldom sick except for an occasional cold. So, it was almost a premonition, that mom frequently mentioned there were two things she was afraid of getting, “old-timers” and cancer. She didn't want to lose her identity and she didn't want to be “eaten up” by cancer. Ultimately, the two conditions she feared most became a reality, yet she was never aware that she suffered from either.

The inauspicious journey, most likely, began long before 1997 when she was diagnosed with hepatitis C. Mom was 63 years old then. Medical management was limited to an annual Alpha-fetoprotein level and ultrasound exam of the liver; otherwise nothing else needed to, nor could be done. Interferon therapy, though available, was fraught with too many side-effects. Thus, she continued to live an uneventful but full life until fifteen years later when she began to

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experience increasing bouts of short-term memory loss, depression, paranoia, delusions and argumentative outbursts. These symptoms, utterly out of character for Mom, were intermittent at first and then seemed to linger, retreat and hide somewhere under a cloak of shadows, only to resurface later in spurts as if to mock those who loved her most. After a series of tests, including a neuropsychiatric workup and a brain MRI, it was deemed she had met the criteria for Alzheimer's dementia. She was then 78 years old and the stage was set for the emotionally charged and painful drama of Alzheimer's to play out its role.

Since the hepatitis C appeared to be under control for all these years, the main battle was to fight the dementia since it had become the most obvious condition that was rapidly affecting her health and safety. Before long, the clues of dementia began to expose themselves more frequently and boldly: accusing others of conspiring against her to steal money; encountering strangers in the house; spoon-feeding a scarecrow figure, believing it was a child dressed up for Halloween. Daily management of the household and the routines of daily living became increasingly difficult and eventually she needed help completing the simplest tasks. The first bout with loss of dignity occurred when I needed to exercise my power of attorney to assume various executive functions. Having always been a very independent person, she didn't like that and as a result was angry with me for a long time; that hurt me deeply. The second retreat from dignity occurred when I reluctantly made the decision to remove her from her home of 40 years. I surreptitiously employed "accomplices" and resorted to chicanery as a means of getting her out of an obviously dangerous situation. It was a heartbreaking event, indeed. Again, she was angry; and rightfully so.

Her physicians prescribed a cocktail of medications to slow down the progression, but side effects from those drugs abounded and she was rapidly deteriorating. Nothing worked until she was hospitalized at a gero-psych unit for aggressive behavior. There, a bold psychiatrist "cold-turkey'd" all her medications and prescribed Depakote only. It was obviously a clinically remarkable strategy, because suddenly her delusions abated and her temperament settled. Thankfully, so full of life, she started playing bingo twice/week, danced to music on holidays, and even helped care for the other residents, believing she was an employee at the facility. I was ecstatic! I finally had my mom back! I could take her on trips and spend quality time with her for many years to come.

When I became confident that the dementia was contained, at least temporarily, she experienced an acute onset of abdominal pain. Gallstones were the culprit, but the CT scan also revealed a large hepatoma in her liver measuring 5 centimeters and the Alpha-fetoprotein level was also slightly elevated. Oh my! The hepatitis C had launched a sneak cancerous attack, and it was a vicious one!

I was then forced to make a decision I was not yet emotionally ready to make. As her power of health care attorney, I had to give the blessing to proceed with a full attack against the villainous cancer. As a physician, I knew about the potent arsenal of weapons—surgery, chemo-

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and radiation therapy—all at my disposal. But, I also knew what it would do to her quality of life. I knew the atrocious and arduous path my mom would have to trek if we fought this battle. Was it worth it? How much more real life, as opposed to just living, would she gain by doing this? She would not understand what was happening to her and fear would be all-consuming. An aggressive counter-attack would disrupt the equilibrium her body had established with the dementia. Contrary to all the knowledge I had gained in medical school, residency training and years of medical practice which may have prompted others to proceed with a treatment plan, I settled upon the most difficult decision: To do nothing—at least as a physician. As a loving son, I was going to concede to the enemies of my mother and let her pass from this life but not without providing all the love and anxiety-free comfort in end-of-life care that any dying person deserved. Hopefully she would pass without further suffering and prayerfully in peace.

I watched her decline over the ensuing months—slowly at first, but accelerating quickly with weight loss and weakness in the final weeks. Thank God my mom didn't know she had terminal cancer. Just three weeks before her death, she casually asked, "Is there something wrong with me?"

"No," I lied. "Why do you ask?"

With a distant gaze, she replied, "Oh, I don't know." Then, quickly, she was distracted and the topic thankfully shifted.

Despite fluctuations of her conscious state and the labored breathing, on the morning of her passing at the Hospice House, Mom's face appeared calm and peaceful. The tenseness of the past few days seemed to be erased. Her hair was combed just right and she smelled so good. It was as if she was waiting to go on a trip—home, perhaps. A small tear had formed at the corner of her left eye just as she passed. A farewell tear, I believe, and not from pain.

Mom succumbed to the two diseases working against her, yet protective at the same time. Through death by cancer, she retained her dignity and avoided further suffering from dementia; the innocence of ignorance conferred by the dementia gave her the sense of immortality.

As she passed, the sun fully broke through the clouds and softly radiated its light and warmth into the room where my mother had taken her last breath. Through death, the brave warrior had become the ultimate victor over two diseases.