Caregiver

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My job as a professor was more flexible than my wife Ruth's job—except for teaching, I had no fixed schedule, but Ruth had to be in her office at 8:30am on weekdays. So our daily schedule was that she would get up, make coffee, bring in the papers, and then wake me. I'd come down to breakfast to find her finishing her oatmeal as she skimmed the papers before showering, getting dressed, and leaving for work. This schedule varied only when, as a metastatic breast cancer patient, she had medical appointments at Northwestern Hospital in downtown Chicago; on those days we got up together, and I'd drive her to the appointments, radiation or chemo, or meeting with her oncologist. That was our routine with me as a caregiver for the three years after her diagnosis... until it wasn't.

On one October, 2012 morning, I woke alone in bed and wandered down to the kitchen wondering why Ruth hadn't awakened me. I found her dressed, sitting at the kitchen table, staring blankly. She couldn't speak. I panicked and called my doctor son-in-law and asked him what I should do; he told me what I should have known: Call 911. The fire department responded immediately and within minutes there was an ambulance and firetruck at my house (they always send the firetruck because they don't know what will be involved in getting the patient out of the house). They put Ruth on a gurney and drove off to the emergency room at Evanston Hospital with me in pursuit. On the way I called my daughter Eve to tell her what was happening and asked her to call her sisters.

Ruth and I waited in the ER for a while until a doctor examined her, saw that it was a neurological matter, and had the neurologist come in. She ordered brain scans and we learned that Ruth had a tumor on her brain near the Broca area which affected her ability to speak. Ruth was admitted to the hospital. The neurologist said Ruth needed surgery. I wanted Ruth to get her medical care at a major teaching hospital, not in Evanston; so, against medical advice, I checked Ruth out and drove her to the ER at Northwestern Hospital, where

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her breast cancer was being treated. After an interminable wait in the ER there she was examined by a neuro-oncologist who ordered scans and then admitted her to the hospital. Soon after, she went into surgery to see if the tumor could be removed; it couldn't be, but they were able to shrink it with steroids and Ruth regained some ability to speak.

The examination by the neuro-oncologist in the ER at Northwestern was unreal and confusing to me. In addition to attending to Ruth's needs, they focused on what I thought mundane arrangements: among the paperwork they had me fill out was a form for the State of Illinois to get a handicapped parking hangtag—I had no idea why I would need that. But they were experienced and I was naive: Once released from the hospital a week or two later, Ruth would need daily treatments; that meant driving downtown daily and coping with congested parking. At first, I parked in the hospital's lot across the street and we'd walk together to the chemo/xray area; after her treatment we'd walk back to the car together.

But the walk was becoming increasingly difficult for her, so I started dropping Ruth off at the hospital entrance, she'd go in and start her treatment while I parked the car. When the handicapped hangtag finally arrived, I would park in a handicapped spot on the street and we'd walk in together. Even that got too hard for her, so one day I dropped her at the door to go in and start treatment while I parked the car. With the hangtag in place, I parked in a handicapped spot on the street (close enough so Ruth could walk back to the car), turned off the engine, and got out of the car. Immediately a rough-looking guy in civilian clothes demanded my drivers' license and the hangtag. I asked who he was and he belligerently showed me his Chicago police ID and badge. He confiscated the hangtag and my license and gave me a citation requiring a court appearance for mis-use of the handicapped hangtag. I tried to explain that I was going to get my wife who needed to walk back to the car with me. He was deaf to my pleas.

This was trouble: not only did I not have the hangtag, but I had to appear in court three months later on a serious charge, at the same time I needed to manage Ruth's treatments. I was beside myself. From then on I would drop Ruth at the door, park in the regular lot, and meet Ruth in the hospital. One day a week or so later, when I met her there, she was in hysteria because she had gotten on the elevator, but forgot where she was supposed to go. She rode the elevator in that confused state until somebody helped her get to where she needed to go. From then on I parked and walked with Ruth so she wouldn't get lost. But that walk was difficult for her, and when the Human Resources Department at Northwestern heard what had happened, they arranged for a reserved parking spot that was an easier walk.

I still had the court appearance looming. My daughter Eve contacted Pam Zekman, a Pulitzer-Prize-winning reporter for WBBM-TV (CBS) News and told her the story. Pam Zekman interviewed us on the air and showed up in court on the day of my trial. It turned out that the cop had been targeting people using handicapped hangtags near the hospital and ticketing them inappropriately, just as he had done to me. When the judge heard the details, he threw out my case and twenty-some others, excoriating the grinning, smug cop. It took several months in total, but we did finally get the hangtag back. . . of course during that time we could not use handicap spaces.

My role as caregiver began to grow much greater—instead of just being responsible for the breast cancer treatment and chauffeuring her for the glioblastoma treatment, I needed to attend to all of her needs. During the next three and half years until her death in April, 2016, she became more and more disabled. Our roles in our marriage had reversed: I became the homemaker and cook, preparing our meals (which I had never done—Ruth was a superb, energetic cook) and taking care of the house. I soon also had to give her showers and dress her (ever try putting pantyhose on an adult who cannot stand by herself?). Then I had to take her to the toilet.

Before long she could not negotiate the stairs without holding onto me; then she couldn't manage stairs at all and our lives were constrained to our bedroom and an upstairs study that I turned into a living room/dining room. We spent all of our waking hours and I brought up all of our meals. One particularly memorable meal was set up not in the study, but in our much larger bedroom. Most of our daughters and many of our grandchildren had come to see Ruth, so dinner for about 20 that night was on folding tables and chairs brought upstairs. As frought as the situation was, I remember that dinner as joyous.

Nights became tortuous with having to take her to the toilet several times each night, interrupting our sleep. Throughout it all, except for some occasional daytime help from our daughters, I was her sole night time caregiver; days and evenings I could sometimes rely on my daughters and some close friends to be with her, especially when I had to teach my classes. But soon her needs were so extensive that I could not ask friends to help meet them, so I hired professional caregivers, but only when I had to lecture and my daughters could not be there. I did not get a full night's sleep for more than three years; I lost 10 pounds; I got pneumonia. My children implored me to get help at night. I resisted because *I* wanted to provide for her, as she had provided for me and our daughters. But eventually I did—it was horrible to move out of the bedroom and sleep alone, after 47 years of snuggling with Ruth at night. Things kept deteriorating: soon Ruth needed a hospital bed. Then she could communicate only in hand motions and grunts. Then not at all. Then she slept all the time, doped up on morphine to dull the pain. Then, while I was making a condolence call to a friend whose wife had just died of breast cancer, Ruth died.

Within an hour the funeral home had picked up her body and the hospice people had cleared away the hospital bed and all of the medical paraphernalia. Ruth had vanished without a trace. And things continued to get worse: now I had to deal with the funeral home, the cemetery, lawyers, banks, insurance companies, Social Security, and on and on. Interminable paperwork in the midst of profound sadness. More than a month of full time busy work that I could not shirk. And every day when I got dressed, there were Ruth's clothes and shoes mocking me in our closet. That was even more difficult than the 24/7 care-giving I had done for so long—at least the care-giving was meaningful. Now there was only pain and loss.

So, what advice can offer to some poor bastard facing the same situation? Be strong; be brave; do what needs to be done and do it well; do it with love and all your heart. But try not to bear the burden alone—force your self to rely on friends, family members, and professionals in order to ease your intolerable life. Seek and accept any help you can get. Work hard to rebuild your shattered life.