



LAST DAYS

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I am an eighty-three-year-old physician living in a retirement community. I had been married to the patient described below for fifty-eight years. During the final two years I served as her full-time caregiver. I wrote what follows

during and shortly after her last five-day hospitalization. She died on November 5, 2011. My wife's name was Mary Jane, but everyone knew her as MJ.

MJ and I first met in Baltimore when I was a fourth-year medical student and she was a second-year student nurse. I was doing an elective in obstetrics and MJ was earning extra money working overtime. I was preparing to deliver a baby when I noticed that the nurse assigned to assist me had a lock of the reddest hair I have ever seen peeking from beneath her hood.

Our first date was to a nightclub, our only visit to such an establishment.

We tried dating others after that first date, but it was soon

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plain that we had become inseparable. Even though I had planned to leave Baltimore for residency training, I applied at the last minute to Johns Hopkins and was accepted as a medical intern at Johns Hopkins Hospital. We married after MJ's graduation one year later, and stayed in Baltimore while she worked, supporting us during my payless residency.

What was MJ like? Many things come to mind—loyalty, love, humor, exciting, challenging—but, above all, MJ always remained her own person while giving me unlimited love and friendship. She could be feisty: In the 1970s while we were in Florida, there was a spate of divorces among medical school faculty. Arrangements were made to provide counsel to the faculty wives. At the meeting, the counselor asked MJ, "What is it like to be married to someone smarter than you?" MJ's response: "And what makes you think my husband is smarter than I am?"

During her last few years I could see her failing; her death was not a surprise. It provided the family relief that we could not deny to a long tenure of pain and discomfort. But her death, its finality, has left me with a void that I doubt will ever ease completely. I am thankful for every day we were together, a message I conveyed to her many times.

November 2011

I sit on a sofa, eight feet from my seventy-nine-year-old wife in the Medical Intensive Care Unit (MICU). MJ was admitted to the MICU four days earlier in acute pulmonary insufficiency, following abrupt onset of aspiration pneumonia. She has the accoutrements of many patients in the MICU—an oxygen mask covers her face, there are IVs in both arms, a urinary catheter is in place, as well as a loosely fastened abdominal restraint applied during an earlier period of restlessness. She is attached to a monitor that graphically portrays her vital signs and beeps annoyingly when it records abnormal values.

I walk to the bedside and brush the hair from her brow. It is still naturally red and still beautiful, the hair that first attracted me to her some sixty years ago. With my mouth close to her ear, I try talking to her. There will be no response, but I try anyway. Events from the past life cascade through my memory. I walk about the room. I peer out the door, looking at nothing. A nurse walks by and asks if I need anything. Am I all right? How do you describe that you feel like someone has a hand in your gut, and is trying to pull something from you?

Twenty-five years ago, MJ began to have severe joint pains. Because we were living in New Jersey, Lyme disease was first considered as the cause. A consulting rheumatologist subsequently diagnosed rheumatoid arthritis. A quarter of a century later, the disease remains active, causing my wife to experience the full gamut of its manifestations and treatment complications. Progressive joint arthropathy required

multiple surgeries on her hands and feet. There have been bouts of sepsis and pneumonias, exacerbated by the aggressive therapies to relieve discomfort and deter progression of her disease. Chronic anemia persists. Osteoarthritis, osteoporosis, and several decades of steroid therapy have contributed to spontaneous fractures in her pelvis and spine. She has lost six inches of stature. In spite of all this, MJ remained physically active until three years ago when her back pain became persistent and severely painful. Pain management specialists recommended low back surgery and para spinal injections. None of these treatments worked. She began using long-acting narcotics supplemented by additional opiates for breakthrough pain, but the therapy was only modestly successful. During episodes of severe pain, I would rub her back to soothe and comfort. To our surprise, this did help ease the pain. Before this hospitalization, pain was becoming refractory to increased doses of narcotics, and sometimes I would do back rubs twelve times a day to offer MJ some relief.

The day before the hospital admission, we were up as usual at 5 AM. I had made coffee and prepared breakfast. The morning newspaper was already at our doorstep and, as was our custom, we read it, kibitzing about items of interest. MJ went back to bed. Later on, after lunch, we drove to a big box store. I would usually push MJ in a wheelchair, though at times she was able to get behind the wheelchair and walk short distances. Her walking capability had declined the past six months. Even a few steps would often precipitate back pain. We replaced our afternoon walks with drives through the rural countryside. These were pleasant interludes. MJ was beginning to spend more of her daytime hours in bed. When awake, she was annoyed by her increasing memory problems. She could not remember what she had eaten at a previous meal, or recall a recent conversation. This evening, MJ was more tired than usual, ate little supper, and retired early. This change worried me as it mimicked episodes that were preambles to earlier hospitalizations. Her most recent stay had been two months ago.

I awoke about 4:00 AM, and reached over to touch her—she felt warm. I roused her with difficulty; though awake, she was obviously confused. She had trouble holding a thermometer in her mouth, but it registered 101 degrees. Transferring her from the toilet to the wheelchair took twenty minutes with encouragement and assistance. I knew she needed hospitalization. I called our daughter Karen, who lives in the same rural community that we do. Karen works as a nurse in the hospital where her mother had been admitted several times. I told her I had to take her mom to the hospital. Karen was already preparing to go to work and said she would meet us there. The trip from home to hospital required an ambulance. Our small community has excellent service, and within minutes after calling 911 an ambulance arrived.

I drove to the hospital, arriving a few minutes before the

ambulance. MJ was taken immediately into the ER. I could not join her until the ER personnel had placed her in a room and begun their assessment. My protestations to the staff that controlled visitors to the ER that my wife was obtunded and would not be able to answer questions were deflected. I was told that the professional staff was most capable, and I would be permitted to be with my wife as soon as they thought it was reasonable. The wait was not long, but it was frustrating. I knew the strange setting with unfamiliar people questioning and examining MJ would add to her confusion. When I was finally allowed to see her, she was in bed. An IV had been started and people were in and out of her room drawing blood, doing an EKG, and taking her for x-rays. They also asked questions and examined her, trying to assess her condition. Once the data were gathered, she was promptly seen by the ER physician, the hospital admitting physician, and pulmonary and infectious disease consults. I was able to help them review her complex and lengthy medical history and recount her present illness. During the early hours in the ER, MJ was awake, cooperative, and able to answer some simple questions. Overall, her mental acuity was sluggish and dull. The assessment was thorough and done quickly and efficiently.

The plan was to admit her to the pulmonary unit but no bed was available. Her condition worsened. She had become more obtunded and, at times, was difficult to arouse. She required oxygen by face mask to maintain proper saturation. She remained in the ER until early evening when a bed became available in the MICU.

During her long stay in the ER, the staff was attentive, supportive, and comforting. Nurses were appropriately aggressive in contacting doctors responsible for her care, especially to obtain orders for analgesics to ease her back pain.

The first day, I stayed with MJ, taking only a brief lunch break. I was able to answer questions for the administrative and professional staff as they readied her for admission. But time hangs heavy waiting in the ER for a room to become available.

During a conversation with one of the physicians treating my wife, I had the urge to urinate. There are no bathrooms in the patients' rooms in the ER. Scattered along the corridors are unisex bathrooms to accommodate visitors one at a time. I spotted two bathrooms, both occupied and each with a person waiting outside the closed door. I kept looking. Being older, and with all the symptoms of prostatism, my sense of urgency was not to be denied. I finally found an unoccupied bathroom, but it was too late. My khaki pants had a noticeable wet stain down the inner side of my left trouser leg. All I could do to minimize my embarrassment was to walk with my head held high and hope that passersby would not notice. As I passed a nurses station, a nurse leaning against its surrounding counter fell in stride with me. She asked me what size pants I wore. Surprised, I muttered, "36." She left at once.

When I entered my wife's room, there were two pairs of clean, used trousers lying on a chair. Both were size 36. The reason for the earlier question was now clear—the nurse had provided two pairs of trousers of different lengths, hoping one would be satisfactory. I have spent a lifetime in hospitals as a clinician, teacher, administrator, and a visitor. Never before had I experienced such unique thoughtfulness. I did not discover the nurse's name to say thank you.

On the second day, the hospitalist who served as MJ's primary physician during this admission wanted to discuss what treatment strategy the family wished the professional staff to take. He said that the hospital record indicated we favored aggressive therapy including a full code for resuscitation. I was surprised to hear this. MJ and I had prepared living wills with explicit directions that neither of us favored heroic measures that might prolong life but had little chance of improving the quality of life.

Later in the day, the pain management physician and the pulmonologist (both of whom had treated MJ during her previous hospitalization) and I met at her bedside. She was unresponsive but restless, and had obviously deteriorated since admission. Unspoken was the realization by all three of us that recovery was unlikely. A treatment plan emerged that we all supported; antibiotics for her pneumonia would be continued, she would receive IV fluids to maintain hydration and kidney output, she would be sedated enough to control agitation, she would be given analgesia if deemed necessary for back pain. The consensus was that this regimen would give her a chance to recover, though this was unlikely. The plan would be reassessed regularly. I thought this approach would meet MJ's approval, a conclusion based on many conversations during the past several years. It also had the support of our three children.

Over the next forty-eight hours, MJ's restlessness eased, she became afebrile, and the need for sedation and analgesia lessened. But she still remained insensate. I spent most of each day in her room. I paced and stood at her bedside. I brushed her hair from her forehead. This last gesture that was focused on her red hair somehow comprehended our life together. It never failed to bring me to tears.

As a physician I knew my wife was dying. It would not be long. I had agreed to the care plan. But there were moments of doubt. Should I have opted for a more aggressive approach? Had I been premature in backing away? I was certain, at least intellectually, that "we"—the family and the physicians—had chosen the right course. I was doing what MJ wanted, what she would tell us to do if she could. Even so, weeks later, I have my moments of doubt.

My daughter Karen has worked for fifteen years as a nurse in this hospital. She had fallen in love with nursing and had gone to nursing school in midlife. Karen tried to ease her distress by working. It was not successful. Her colleagues encouraged her to return to her mother's bedside, where she



Richard and Mary Jane Reynolds in the late 60s.

was also support for me. We sat silently on the sofa. When one of us said something, it was usually an anecdote, often humorous, from times past. We smiled and wept at the same time.

MJ and I had moved to Ohio two years earlier. Throughout my working life I had changed jobs several times, living ten or more years in Maryland, Florida, and New Jersey. We had retired to Florida, but I continued to teach and serve on committees at the medical school where I had been a faculty member twenty years before. Seven years later we moved to south Florida, where I tried unsuccessfully to help a community hospital transform into a

major teaching hospital so that it could become part of an academic health center. After five years, MJ decided she wanted to be closer to family. Our children Wayne, Karen, and Stephanie lived in California, Ohio, and England, respectively. We decided to move to Ohio where Karen and her son were.

During MJ's third day in the MICU, a member of the hospital's palliative care team met with me. Her task was to prepare me for conclusions to the admission other than death. I was prepared for MJ to die, but suppose she didn't? What were my thoughts and plans? Previous hospitalizations had been serious enough to raise similar questions. During those

episodes, I had been confident that she would recover. Each time I brought her home and together we would try to capture a semblance of a quality life. This time I did not feel that way. Now my fear was that any improvement that postponed death might leave her bedridden, obtunded, or even comatose, which would require a level of care that no one person could manage at home.

I remembered an earlier life-threatening illness at another hospital that required a week in the MICU. Our daughter Stephanie, an Anglican nun in a convent in Oxford, England, was visiting us at that time. “Dad”, she counseled me, “there comes a time when you must let Mom go.” Intellectually, clinically as a physician, I understood. But “letting go” is an emotional challenge. This time I thought I was ready.

The palliative care attendee had a nursing background. She put together a list of nearby facilities to care for MJ if she should live but remain unresponsive. I was at the stage where I wanted her to die and was afraid she would not. We had discussed this dilemma and had prepared living wills cautioning against heroic, aggressive treatment in a dire terminal state akin to MJ’s current condition. MJ had even threatened me that if I disavowed her wishes she would return to haunt me. But all that preparation is not enough to erase all doubt or reassure that you are making the right decision.

The palliative care professional nudged me toward my wife’s bedside as she left. She said I should give MJ a hug and a kiss. She added that I probably would like to comfort her by crawling alongside and entwining our legs. These are not her exact words but they relaxed my face into a faint smile. My God, I thought, is the love and lust of an eighty-two-year-old man for his wife in the throes of a terminal illness so obvious?

MJ died on the fifth hospital day. She had remained unconscious since the first day.

The last days were a continuation of the preamble. MJ never responded. She developed a cardiac arrhythmia with tachycardia that was not treated. Respirations become more labored, and it was now definite that death was the only conclusion. There were no abrupt changes. On the final day I went home to shower and change clothes—I needed a break in the vigil. As I entered our home, a forty-five-minute drive from the hospital, the phone was ringing. It was Karen, who had remained with her mother, telling me MJ had just died.

I returned at once to the hospital. Karen was still with her mother. The staff had closed the door to the room and pulled the curtains together that covered the window facing the inside corridor. Karen and I hugged and said little. We were alone in the room. After awhile, without words spoken, we left.

After MJ’s death I went to the funeral home for the required identification prior to cremation. Karen and Wayne were with me. MJ was laid out in a room by herself. She looked comfortable. Her hair, still naturally red, spoke to me

of the beginning and end of our journey together. I imagined her saying: “Dick, it’s all right. I don’t hurt anymore. It was my time. I love you.” Our children and I hugged, wept. This was goodbye.

I want this essay to be a celebration of life, love, marriage, and MJ. It is our story. I grieve, I am sad, but I’m doing fine. I remember Lou Gehrig, famed Yankee player, who said as he addressed the fans at Yankee Stadium shortly before his death: “I consider myself the luckiest man on the face of this earth.” I think I can tell Lou Gehrig to move over.

Coda

I have shared this story with family and colleagues. Many have said they are deeply moved or touched by it. Some are uneasy about its frankness and its rawness. Why are you writing this, they ask, and for whom? I am not sure I have an answer. Throughout my professional life I have recorded observations, ruminations, and wonderments about daily events. I have filled notebooks with these musings. So the habit of writing about events may represent the hidden diarist that is part of me. But it was different this time.

As a clinician I have helped—or tried to—many patients and families through similar situations. During my first years of practice in a small western Maryland city, I recognized that despite my excellent clinical training, I came up short in providing them with comfort and wisdom. Later on as a department chair, I established a division of humanities. I never could set aside Thomas Mann’s phrase: “Medicine, that subdivision of humanities.” I would have liked to discuss with him his interpretation of this comment in *The Magic Mountain*.

I was not naive when caring for my wife during the early and late stages of her illness. I had witnessed similar situations in other patients and friends as they were dying. This was different. I began to doubt my clinical judgment. I was uncertain about previous decisions my wife and I had made to cope with death’s intimacy. I could see how even meager hope could push patients and families toward unwise therapies.

I was not depressed or troubled with guilt. I did not realize, however, the degree of sadness or emptiness I would experience. Even now, I weep as I reread these lines. If there is any take-away message from my story, it is that no matter how knowledgeable, how prepared an individual is for situations like this, it is still likely that the doctors, the health professionals in attendance will underestimate the hurt (I wish I could find a better word) that is occurring among the patients and their families.

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