

Helping Mother Die

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There are days you will always remember. December 5, 2009 my mother called and told me her friends commented she looked sick. She was jaundiced. I had just seen her on Thanksgiving and she seemed to be herself. She ate the Thanksgiving meal and appeared to have her usual appetite. She also had enjoyed one of our favorite family pastimes with her grandchildren, playing the card game whist. There was a cacophony of laughter coming from the dining room that night for hours as she masterfully played her high bids to victory. During November she was still doing all of her usual activities: line dancing and playing cards at the local senior centers, bowling, ballroom dancing, and singing in the church choir. That is why the phone call that night was somewhat surprising. She had been calling me in the past month with some non specific gastrointestinal complaints that she attributed to her metformin medication. After she consulted with her doctors, she was feeling improved without the medication during the past 2 weeks. Painless jaundice, though, made me very suspicious that she had a serious problem. My instincts would be proven correct.

That night, I joined her at her local hospital emergency room. The staff members were so friendly. The administrative assistant took me to her ER room. She was lying comfortably on the stretcher, obviously quite jaundiced. I was crestfallen immediately but remained calm. I explained to my mother what tests she should expect (laboratory work, CT scan). The nurses and the ER physician were polite and respectful to my mother and me. The results confirmed my suspicion. She had a large mass in the head of the pancreas. The ER physician came back to her room and delivered the sad news. My mother has always been a very stoic and quiet person. I noticed a slight glaze to her eyes with some tears. I think she understood well her prognosis could be grave indeed. In retrospect, she recounted having lost 10 pounds since the summer. In the recent month, she noticed dark urine and light stools. I next called my good friend, Sunil, from the emergency room late that evening. He is a gastroenterologist at my hospital. He helped me arrange for her to get an ERCP and biliary stent for Monday morning.

Being on the staff at a large academic medical center for fourteen years, I knew many of the specialists quite well. On review of her abdominal CT scan, it was clear she would not be a surgical candidate due to her advanced disease. The surgeon being mindful of our predicament offered his wisdom. We should be preparing for much heartache ahead. The ERCP specialist placed the stent that morning without difficulty. There would be several more consultations and evaluations in the following days. Ultimately my Mother would discuss her prognosis with her local oncologist. Mother had early stage breast cancer several years earlier without recurrence. She liked her oncologist very much and trusted her opinion. Their decision was no chemotherapy because of the very limited response rates. She entered hospice only 10 days after her diagnosis.

My mother was a widow since 1984. My father died of asthma/COPD at age 54. Then she made a new life with her new companion, Tony for fourteen years. Tony died in 2005. He had advanced pancreatic cancer and lived only 9 months after his diagnosis. My mother had observed his course of illness from the bedside those 9 months. Tony had decided to have Whipple surgery at the onset of his diagnosis. The surgery initially was helpful in relieving his biliary obstruction in combination with a biliary stent. But later he went on to have problems with post operative small bowel obstructions. His quality of life never improved and he slowly deteriorated living the last several months in a local nursing home.

So my mother knew exactly what might happen to her in the upcoming months. She made her wishes very clear to me. I was the health care proxy and the only health professional in the immediate family. She wanted to pass away as comfortably as possible in her home. I told my brother she might live as short as 2 or 3 weeks, or perhaps 9 months or longer. Meeting with the hospice nurse at her home, I helped my mother explain her symptoms and medical needs. The nurse initially warned me to be her son not her doctor. I think she quickly discovered that I could provide some important background details when my mother was unable to do so. During the next few weeks it became apparent she would decline rapidly. She never really regained much of her appetite. By December 18th, we started to notice some mild delirium. She suffered indignities with malabsorption from her biliary obstruction causing fecal incontinence on a few occasions. Her pain was manageable at 5 out of 10 on the visual analog scale without any narcotic medication until the last week of her life. She had one night of severe pain on

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December 24th for about 10 hours. With her body shutting down and aggressive pain management, she passed into a state of unresponsive on December 25th at 1230PM. Her hands were warm for hours as I sat beside. Then as her breathing become more agonal, her hands turned cool and cyanotic. Her eyes opened wide at 330AM on December 26th and then she heaved her last breath. I kissed her good bye and told I loved her one last time. I combed her hair and sprayed on some of her perfume as we awaited the funeral home visit. She was now at eternal peace dying in her favorite recliner in her living room.

At times, others in the family wondered about other approaches. The last week she needed 24 hour supervision and we patched it together with family and friends. One family member thought she would be better cared for in a nursing home. Certainly this was not my mother's desire. In the last 2 days of her life, another family member thought the

pain medication was causing too much sedation (I later found out this is called "double effect" with terminal sedation). When offered the chance to discuss her pain management with the hospice nurse in her last week she was unequivocal in her wish to remain as comfortable as possible with assistance of narcotic medication. Then another family member at her side on December 25th after she had slipped into a comatose state wondered if she was experiencing any physical pain. I reassured her, I did not believe so.

This is how we helped mother die. Mother had accepted her circumstances with immense grace. I think her spiritual life helped. There were no complicated beliefs or theology, just her readiness to pass on. I had made a vow to myself many years ago that I would be with her as much as possible if this circumstance ever occurred. Mother's wishes were fulfilled and so were mine.