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Learning from the Death of a Parent

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On October 21, 2014, my mother died. Even at 97.5 years of age, we were still surprised at the events which resulted in my mother's death. Perhaps the most common question I have been asked by patients is, "Mother was doing well a week ago and now you say that she is dying; why?" The implication is that surely there is something that can be done or that should have been done so as to have avoided this condition. When my father was in his last illness, I sat by his bedside through the night. One night, I passed the time by imagining, "Whose fault is it that my father is dying?" I already knew the answer and that is that no one was at fault; the reality is that dying is a part of living, but I went through the list: my mother, my father, his doctor, the hospital, others. The truth was that my father's condition was due to his age, his habits and to life. Often, we try to comfort ourselves by blaming someone for the circumstances of life when, in fact, more often than not, no one is at fault.

Eight weeks before my mother's death and four weeks before she began to deteriorate rapidly, my family and my mother visited the places of her childhood. We visited the last home her parents occupied before their deaths and the locations of communities where she lived but which no longer exist. My mother walked to those places and we had a wonderful trip. For years, I have said to my family and particularly to my father and mother, "We never know when the last time is the last time, so we make sure that every time is a good time so that if it is the last time, it's OK." At the end of this day, I embraced my mother and said, "It was a good time, wasn't it?" She said, "Yes."

I suspect that I know what caused my mother's death. She lived alone but progressively needed more help than we provide at home. So, we talked to her about assisted living. She was terrified of nursing homes and thought every residual care facility was a nursing home. The day we addressed assisted living and immediately upon our leaving, our mother called an ambulance and went to the hospital. That was the beginning of the end. "If we had not addressed assisted living would she have died?" Less than two weeks later she had a massive stroke and never woke up.

Would this have happened if we had not broached the question of assisted living? I don't know but I do know that the circumstances and needs which led us to take those steps were real.

Many of the questions I have answered for others over the past forty years became my questions. When as a physician you know all or almost all of the answers to the most commonly asked questions, it does not make those answers easier to accept. "Knowing" often only adds to the questions because alternative answers are within your discretion. It does not make those alternative answers valid or acceptable but they are there and only wisdom and resolve keeps you from making them. Often making the wrong answer to these alternatives involves the decision makers treating themselves and their feelings rather than treating the

patient and their best interest.

It is not uncommon for elderly people to imagine that others are trying to take advantage of them or to harm them. In this state, things can be said that are hurtful but those who know the truth and who now are responsible for making decisions must understand that the accusations are not about real threats but only about imagined fears. Often, it is as if the child has become the parent. My parents were never unkind to me when I was a child, but they never worried about being my friend. They were my parents which meant that they often denied me what I wanted but did not need and they didn't see that it was their responsibility to allow me to avoid pain or disappointment. That same principle applies to the child who due to the parents' age and illness, the child must make difficult decisions.

All of the above will seem like child's play in contrast with the issue of how care should or should not proceed. At 97, the decision for a person or family to invoke a "do not resuscitate" (DNR) order should be simple. I made the personal decision at 50 that I did not want to kept a live by extraordinary means – ventilator, artificial or forced feeding, or hydration -- if my condition and health warranted a DNR. My mother had been DNR for a number of years but now new questions had to be answered; and they had to be answered by the children.

The major struggle came when ten days into her illness my mother had a severe stroke and became comatose. As we did with my father, when mother's condition became hopeless, we placed her on inpatient hospice care. The question was whether to continue medications and artificial feeding and hydration. Medical ethics does not require extraordinary means of hydration or nutrition. Here is where knowing more helped. Having personally reviewed the CAT Scan and having a reasonable estimation of her prognosis, comfort care was the rational choice.

As the time stretched into three, four and five days, knowledge became an enemy. I knew that I could keep my mother's body functioning with hydration and nutrition, but I also knew that it would not change the ultimate outcome but would only prolong her vegetative state. Being pro- life means also being against euthanasia. I would do no harm to my mother by administering anything which would accelerate her deterioration but certainly withholding nutrition and hydration was causing her deterioration, thus the potential dilemma.

I looked daily for signs of cognitive function; there were none. I sat by my mother's bedside, talking to her – knowing that the last sensory perception that leaves the body is hearing – and looking for signs of conscious response. Again, there were none. Tomorrow, November 4th, my seventy-first birthday, marks two weeks since my mother's death. It is hard to be anything but grateful for the life my mother lived. Since she met my father in 1940, my mother had never wanted for food, shelter or stability. That was not because my parents were wealthy but because they were frugal. They truly lived a "wonderful life." Her death was not my struggle but it was my mother's dying which caused me angst.

As I continue the grieving process, I realize that as my parents made decisions for me when I was a child, which decisions caused me pain or disappointment; they must certainly experienced angst. They could have given me everything I wanted or avoided everything

which caused me pain or disappointment, thus avoiding discomfort for themselves, but certainly not preparing me for life. So, it is that making the right decision for my mother, treating her with dignity and compassion, and not simply acting to avoid pain and discomfort for myself, did cause me angst. As my parents bore the decision-making burden for me, my brother and I had to bear that burden for them. Life is filled with ambiguity. There is no absolutely right answer to those questions but when we act out of love, compassion and principle, we most often will make the right decision and when we don't, we once again have to accept our imperfection.

In the future, the shared-decision making between me the healthcare provider and the patients with whom I work will be assisted by my personal experience. As I share with them my journey, it is my hope that the burden of their journey will be lightened.