

Trusting others to make end-of-life decisions

By Marian Knapp

Over the course of 10 years I made end-of-life decisions for three unique individuals: my mother, my aunt Lena, and my cousin Fred. I was the health care proxy for all of them. In spite of good care, thoughtful interventions, and supportive environments each was on a path towards dying. Frailty was the only thing they had in common.

It's easiest to start with my mom because hers was the simplest decision. I, and my siblings, knew her well enough to anticipate her wishes with certainty. After having lived independently until her early 90's, she entered a nursing facility because she needed 24-hour care. She signed a Do-Not-Resuscitate order. At first she seemed to adjust - talking to people, participating in activities. But most of the time she just sat - waiting. Over three years she became less engaged and more inert. Then she stopped eating. I figured she didn't like the food and made special things. But when I presented the fork she clenched her mouth shut. One day I offered egg salad (her favorite) and she slapped my hand away. Stunned at her aggression, I finally realized it was her way of telling me she was ready to die and I needed to let her go. It was her decision - not mine. So I stopped trying and, together, we waited quietly until she died peacefully a few weeks later.

Lena was different. The same age as my mother, she was determined to live. At 93 I admitted her to rehabilitation after she became dangerously thin and was constantly trying to undress. She refused to sign a DNR order. The medical staff suggested that I sign. My two adult sons said I should but her sister-in-law Celia said, "Lena would want you to do everything to keep her alive." What was I supposed to do? Here was a woman who wanted to live and I had to decide if I could honor her wish. But Celia called back with a gift of trust. "Lena probably would not want to live in that condition", she said, "and, besides, it is your decision and I will support whatever you think is right." The next morning, as I was leaving to sign the DNR, the doctor called to say Lena had died during the night. She spared me the act of signing but not the agony of the decision.

My cousin Fred, just a few months older than I, began having seizures when he was a toddler. Epilepsy was poorly understood in the 1940s, and treatment, it seemed, was largely an uncharted field. No matter what therapies were tried, Fred continued to seize, fall, and suffer head injuries, which ultimately limited his capacity to understand complex issues. In his late teens, when his parents could no longer take care of him, he was placed in a state hospital where he lived for about 40 years until the Department of Mental Retardation's de-institutionalized policy moved him into a group home. When Fred's parents died, his brother, Arthur, took over responsibility. When Arthur was dying from cancer I agreed to watch over Fred. After a few years, he began to aspirate food resulting in multiple hospitalizations and debilitating pneumonias. Fred never had a legal guardian but his care team suggested I become his health care proxy. The law requires that, without prompting, an individual must name someone to make decisions in the event they are not able. The problem was that Fred couldn't understand what that meant. He kept saying he would make decisions for himself. Finally, with several witnesses present, he named me as his

decision-maker. There were only two choices - a feeding tube or not. I wrestled with what his parents or brother would have done, and consulted with his niece. But, ultimately, decided not to order a feeding tube knowing that it wouldn't prevent ongoing problems. Hospice was brought in and, after several pneumonias, Fred died at home among friends.

Three people – one who wanted to die, one who wanted to live, and one without the capacity to make reasoned choices. Making decisions for someone close to the end of life can be daunting or relatively simple. It depends on whether careful planning and communication occurred well before the approach of death. I learned, through hard experience, the necessity of naming a proxy and providing enough information so she or he can decide with as little anxiety and guilt as possible. I experienced the ordeal of making a decision contrary to someone's wishes. Most importantly, I discovered the power of trust - a gift that only we can give to those who will carry out our own end-of-life decisions.

For conversation contact Marian on her blog voicesofaging.com.