ADVOCATING FOR THE DYING

The View of Family and Friends

by Anna Moretti

Imagine you are being forced to play a game. You don't know the rules. People playing the game with you know the rules but don't bother to explain them. They can be changed at any time, depending on who is in charge. Some rules aren't even written down. The stakes are high. In fact, they are life and death.

This is what individuals who are attempting to advocate for a dying loved one experience. Even with written advance directives, discussions, and the support of family and friends, appointed health care agents and surrogates often face a daunting task and are left on their own to determine how the health care system works.

Caring for dying people has been a privilege. As a critical care nurse, I assisted in saving many lives, yet was troubled by the death-defying tactics employed for those whose "lives" were, in reality, gone. As an attorney for Choice In Dying, Inc., an organization dedicated to giving people information about end-of-life laws and putting those laws into clinical practice, I spent years listening to and assisting patients and family members who were in crisis. As a friend, I advocated for a colleague who wished to have life support removed after pancreatic cancer had taken energy and life from her. It is from these perspectives that I write about the importance of advocating for the dying.

A View from the Bedside

As a nurse, I saw family members struggle with the slow and invasive process of death in acute care settings. Standard invasions, including chest x-rays, EKG, central lines, ET tubes, NG tubes, foleys, rectal tubes, and IVs, stood between patients, their loved ones, and death. Family members did not know what to ask nor what to do. They seemed to reason that if doctors and nurses continued aggressive treatment, then their loved one must have a chance of getting better; surely someone would tell them if there was no hope of recovery. Furthermore, withdrawing or withholding treatment was frightening, and asking the physician to stop treatment might mean that they wouldn't have nurses by the bedside or daily visits by teams of physicians.

I remember a patient who had made a video tape of her wishes to convince the next physician who took care of her NOT to intubate her. She had long out-lived her cancer prognosis and was ready for the next infection to be her last. She wanted a dignified death with her family at her bedside. However, with little discussion, she was intubated, given every procedure, and died after twenty-four days in the intensive care unit. I watched this family and many others struggle painfully, not knowing what to do. As a nurse, I struggled with my inability to assist patients and families effectively, and to ascertain that their decisions would be honored.

A View from the Legal Side

Following my years as an ICU nurse, I approached health care from a legal perspective with enthusiasm and zeal. I was encouraged and comforted to read the cases of Karen Quinlan and Nancy Cruzan, excited to hear Bill Colby, Nancy Cruzan's attorney, speak at my school's Law Day banquet. I believed that the laws had changed, that patients really *could* determine the manner of their death. Refusing or stopping treatment *was* a choice. Health care providers were obligated to follow the laws and would be held accountable if they didn't. Right? Well, not really.

As the attorney for Choice In Dying, I listened to case calls from patients and families forced to play the end-of-life game without so much as an instruction book.

Despite changes in the law, the ability of patients and health care agents to determine what treatments they want or do not want is often overridden by health care providers who assume authority and power to do what they believe is appropriate for patients, regardless of the patients' wishes. The impact of this is felt by families who call Choice In Dying.

Imagine watching a loved one die. You have little knowledge of medicine. You are frightened and only beginning to grasp the thought of life without your spouse, your parent, your child. You are asked to make immediate decisions without much information and have no idea about the ramifications of your decisions. This is the typical situation at the beginning of a Choice In Dying case call.

Myths and Misconceptions

There is law, and then there is the "law" that exists in the hospital. Often hospitals develop patterns, a "that's the way it's done here" routine that physicians are unable to change or are too busy to do so. Families call groups like Choice in Dying when things don't seem "right" in the hospital and questions go unanswered, when the "that's the way it's done here" precept doesn't feel right or just. This is how it started for Mr. M.

A coworker who took the initial call asked me whether I had ever heard of a law that states you can't give morphine when the patient's blood pressure is under one hundred. Assuming the family misunderstood the information given them, I asked that a family member call me so we could be sure that the patient was receiving some type of pain management.

Mr. M. called within the hour and explained that morphine wasn't the real issue. His mother-in-law, who lived with him and his wife, was ninety-five years old. She was bedridden, blind, deaf, and had a long history of congestive heart failure. He had intended to keep her at home but

became concerned when she became progressively short of breath. He thought she might be in pain. When he arrived at the emergency room, he was asked whether he wanted her to be placed on the ventilator. He asked what would happen if she wasn't placed on a ventilator and was told, "She will suffocate." He agreed to the ventilator.

After two weeks, her kidneys began to fail. The care team suggested dialysis. Mr. M. refused and began to ask about stopping all treatments so that his mother-in-law could die. She had a living will and he was the appointed health care agent. The resident explained to Mr. M. that he would speak to the attending physician but it was his understanding that "they didn't do that here," that it was against the law to stop treatment that had already been started.

We faxed Mr. M. information clarifying the law so he could speak to the physician. The next day the hospital attorney advised the physician not to stop treatment. Mr. M., confused and distraught, asked me to speak to the attorney.

Reluctantly I agreed. I asked her to explain the basis of her recommendation. The physician, she said, had confirmed that congestive heart failure was a reversible condition, and that this woman could "recover" and make her own decisions about her treatment. I reminded the attorney that the woman we were discussing was ninety-five, blind, deaf, with congestive heart failure, respiratory failure, renal failure, and now sepsis. This angered her and ended our conversation.

My frustration was palpable. I suggested an ethics committee meeting. But Mr. M. had had enough. Instead, he proceeded in the same manner in which he was being treated — force. He went to each provider involved with his mother-in-law's care and said, "If you do not stop, I will sue you." His mother-in-law was transferred out of the ICU and died less than twenty-four hours later.

Mr. M. weeps when he re-tells this story. He explains that he felt he was treated like a criminal. He was told that if he didn't want his mother-in-law to be treated, he should not have taken her to the emergency room. Certainly, a nurse suggested, he should never have agreed to the ventilator. Perhaps, suggested a resident, Mr. M. was tired of caring for his aging mother-in-law.

Clearly medical and legal professionals are in the best position to make this process less contentious and painful for patients and their families. It is their responsibility to prepare families for what it is like at the end of a struggle with a particular disease; to suggest options such as hospice; to educate staff about end-of-life decision making. Moreover, house counsel or ethics committees should educate medical staff about patient's rights. Many health care providers are not aware that there has never been a successful lawsuit against physicians, administrators, or any other health care provider for honoring a request to withhold or withdraw life support. More importantly, most providers are unaware that nearly all advance directive laws explicitly provide immunity to health care providers who withhold or withdraw treatment in accordance with a patient's wishes.

Regardless, unwanted and unwarranted treatment continues. Frustrated patients, families, and loved ones currently apply claims of medical battery and negligence to the nonconsensual use and continuation of life support. While battery actions are certain to effect changes in the behavior of health care providers and administrators, they should be a matter of last resort. More litigation in a field overburdened with malpractice and negligence suits will only make relationships between providers and families more tenuous. Unfortunately, this seems the only recourse for families. For providers, suffering and death is a daily occurrence; for families these things can be a painful, filled with "would of, should of, could of" memories. Powerlessness and injustice force ordinary people to take extraordinary measures. Families often feel that the courts remain their only avenue to capturing the attention of the medical profession.

A View from a Hand Holder

Having worked in the clinical world, I know how hard it is to place suggestions into clinical practice. I have advised families to "move Mom to a different nursing home," "get Dad on a medicine service," "move grandma out of the ICU" and "refuse tube feeding." I also tell families these things will be difficult. I was reminded just how difficult they can be when my friend K. entered a large teaching hospital.

Within three months of her original diagnosis, pancreatic cancer, I stood at K.'s bedside knowing she was dying. She knew that the cancer would eventually kill her, but she refused to believe that the pneumonia that had placed her in the hospital would shorten the journey. She wanted to fight it out. She was appalled when the team of oncologists walked into the room and suggested she sign a do-not-resuscitate (DNR) order. Not once since she started on an experimental protocol did anyone mention that she might die this quickly. I sat at her bedside knowing that we were headed toward making difficult decisions.

No act was more difficult than trying to secure K.'s wishes in writing. I sat for hours watching her breathing and vital signs change. She smiled every time the nurse asked her how she was feeling. I watched her oxygenation dive as the nurses' aide insisted that she move from the bed to the chair so she could change the linen. The ICU nurse in me began to wonder how quickly the code team could get her back into the bed. I scanned the room for equipment, my own pulse and breathing becoming more rapid. After she was back in bed and breathing at an acceptable rate, I attempted to talk to her about her options.

Knowing K. as I did, I believed she would appreciate a logical and systematic approach to her situation. Our conversation was brief and clear. She still wanted to fight. Her decisions were consistent with who she was. I took a new approach. We agreed that there was a possibility that she would lose consciousness during this battle. Agreeing that she should appoint her son as health care agent, she signed the documents and fell asleep. I handed the paperwork to the nurse so it could be placed on the chart. K. awakened a few hours later and gave her son, parents, and friends instructions regarding her wishes: "Don't let me linger. I don't want all of you hovering over my bedside — once it's over, it's over. Stop everything once I'm unconscious." It was a compromise. She would end up being coded and, if successful, on a ventilator. However, she would die believing she was fighting. I left the hospital knowing her wishes and confident the legal documents were in place to secure those wishes.

As predicted, K. coded in the early hours of the morning. I arrived to see my friend muzzled by tube and tape; blood stained the pillowcase and sheets below her head. The DNR order was signed.

I noted that the nurse's visits diminished. In five hours, K. was never turned, repositioned, or suctioned. K.'s mother told me not to create a stir. At least they were allowing her to sleep in the room and she didn't want to chance losing that privilege. The next day I learned that K. had attempted to extubate herself in the middle of the night because a mucus plug had clogged her ET tube. I approached K.'s son and mother about the nursing care. Again, they didn't want to complain. Another day went by and K.'s son began to ask about removing the ventilator feeling that this was exactly the situation his mother wanted to avoid. We asked the nurse to contact the physician and were told that he was busy in clinic and would be unable to see us before three that afternoon. K.'s son explained the importance of the conversation, that he wanted to discuss removing the ventilator so his mother could die peacefully. The nurse's "we don't do that here" response stopped me cold. Surely she was mistaken. This was a huge teaching hospital. We all knew K.'s wishes and her son was her health care agent. Perhaps the nurse didn't know K.'s prognosis. Surely her physician would agree. After all, he didn't want to intubate her in the first place. I assured K.'s son that we would get this straightened out.

By five o'clock that evening the physician still hadn't come. Instead, a patient advocate arrived and explained that "she had heard" we intended to remove the ventilator. She wanted us to know that the law didn't allow for treatment to be stopped once it had been started. Surprised when we asked to see the written law, she explained hastily that it came from the state's law on advance directives. If K.'s son had been alone, he would have believed her statement. Instead, we asked to speak to her supervisor.

The person in charge of patient advocacy was kind and gentle. She apologized for her employee's misunderstanding of the law and explained that she was in the process of calling the ethics committee together. The steps seemed out of order to me, but I assumed that this was the normal process in that hospital. It wasn't; the reason for the ethics committee consult was that K.'s physician was unwilling to remove the ventilator.

The next day was painful. Nurses avoided coming into the room. Unknown, well-dressed visitors began to poke their heads in. We were aware we were being discussed in hallways and behind nurse's desks. At one point we were sitting together, laughing about K.'s amusing habits and remembering her as a mother, friend, and as a boss. Our method of grieving seemed inappropriate to the nurse who walked in and stated that we didn't look like a family who was sad to see K. die. We felt scolded and guilty. I was stunned but too sad to do anything about it. I had faith in the process. I had helped people get through it hundreds of times. We just needed to be patient.

Before my sadness turned to anger, K.'s family asked me to participate in the discussion with the physician. K.'s parents and son sat in small, cramped chairs. The physician stood above them, propped against a small ledge. The patient advocate stood at one end and I stood at the other. The physician began, explaining about treatments for cancer and reviewed K.'s "improvement" on the experimental protocol. My eyes grew wide as he told this family that K. could get better. Doing this, just as the family was beginning to come to terms with death, seemed cruel. And then there was one, final assault. Perhaps, the physician suggested, they were the ones who were suffering, not the patient. His accusation pressed down heavily on everyone in the room. I watched K.'s father's hand grip his cane. I watched the patient advocate shift her weight, uncomfortable with the conversation. I quickly moved into cross-examination mode, reminding the physician of the less-than-aggressive nursing and respiratory care K. had been receiving. He admitted, then, that it was unlikely she would ever get off the ventilator, that she was in the terminal stages of her disease. When pressed, the physician explained that his religion precluded him from taking a life by stopping treatment. He felt morally and ethically obligated to continue life support once it had been started. While I respected his beliefs, I was annoyed that this fact had never been disclosed. The decision was based more on the provider's beliefs than the patient's wishes and medical condition. The ethics committee met, made relevant suggestions, and the process came to a close.

Ultimately, K.'s wishes were fulfilled. A new physician and nurse, holistic and gentle in their approach, came in. I stood at K.'s side as they removed the tube and helped the nurse make the room as peaceful as possible. She died within minutes of extubation with her family and friends at her side.

A Glimpse into the Future

We have an endless supply of laws, studies, policies, and procedures to insure that everyone act compassionately. I'm not certain that it has helped.

Negotiating one's way through end-of-life decision making is difficult, even when you know the rules and understand how it should proceed. It is important that organizations like Choice In Dying continue to serve the public's need for information. Clinicians, policy makers, lawyers, and administrators involved with end-of-life care must recognize that the public's patience is frayed. Advance care planning is our right; honoring it is a professional duty.