

# Will My Wishes Be Honored?

## Carol's Story

My parents moved to Maine so that we could help care for them in their last years. We knew what was needed and thought we did everything right. Dad cared for mother as long as he was able, but eventually, she needed more care than he could provide and she was placed in a nursing home. It was a very difficult decision. Dad received hospice care and died a peaceful, good death. Several years later, we got the call we had been dreading, Mom's vital signs were not good. She rallied, but three days later, a night nurse called and said they were transporting her to the hospital. We said, "No, we have a POA". The nurse replied that we did not have a "do not hospitalize" order so the POA didn't matter and Mother was sent to the hospital. At the emergency room she was subjected to invasive and painful tests and procedures. We could hear her screaming in pain. When the ER nurse said that we do not have to continue this, we asked what to do. He said to tell the ER doctor you want nothing more done. We did this immediately. It was about four hours later when the doctor wanted to put her in ICU. I said, "She doesn't need intensive care, she's dying," and he agreed. We left for about an hour. When we returned a nurse stopped me and said my mother had died about 10 minutes earlier. Why did my mother have to die under such horrible circumstances? Who was responsible for her being taken to the hospital against our wishes? The nursing home, the doctor, the nurse, or did I fail somewhere along the line? The POA gave me 'the power to consent to giving, withholding, stopping any healthcare treatment, service or diagnostic procedure.' Why did it take an ER nurse to end the senseless pain and suffering?

## Highlights from the focus group

### Education

- K-12
- Seminars
- Health care curricula
- Law Schools
- Print and broadcast media

### Standardization

- Protocols
- Tools
- Best practice models
- Training

### Consumer issues

- Advance Directive conversation
- Central registry
- Education
- Impact of diversity (gender, race, religion, age, economic status, etc.)

### Provider issues

- Staff shortages
- Training
- Regulations / Licensure
- On-call issues

### Other Comments

- Promote integrated training
- Work with special needs populations
- Involve faith communities
- Engage families in discussions
- Insure portable, standardized advance directives
- Address accountability within the health care community for not honoring wishes

## Myra Christopher

"People should have the right to be self determining, to be autonomous and to name others they trust to be their decision makers when they no longer have capacity. The vast majority of us will not have capacity at the time of our death. Any valid expression of a patient's prior wishes, whether verbal, written, or video taped should be honored."

## Carol Schoneberg

"Technology has a lot to offer and that can give rise to some very hard decisions. The same technologies that can support life and help our bodies heal, when that's what we want, can also be used when our bodies are no longer able to heal. This technology can add a lot of discomfort as well as pain and suffering. Someone needs to decide how much and how long these treatments are going to be used and is there a point at which being comfortable and free of pain should have priority over invasive tests and treatments that are aimed at the disease. Ideally, it should be the patient that guides these decisions, but when they can't speak, someone else must decide for them. When looking at advanced care planning you assess your current health status, your values and goals and what it means to you to live well at the end-of-life. It's about personal goals, not the goals of the healthcare provider. We may need advocates to get this message across."

## Laurel Colman

"In certain populations it becomes difficult to illicit advanced directives. Patients suffering dementia or Alzheimer disease are especially difficult cases. We can have great policy, great forms, and a great staff, but the conversation about patient wishes needs to happen years before, not at admission to a nursing home."

## Deb Alpern

"When a patient is ready for discharge from the hospital, we need to be aware of perhaps the greatest barrier of all to honoring patient's wishes: the imposing of our own views on patients and families. This is not about us, or what a health care provider would choose in the same situation."

## From the facilitated discussion group

A number of issues were identified as barriers to honoring the wishes of a dying person: the lack of uniformity and limitations of advance directive documents; failure of patients to express their wishes while competent; lack of a central repository for advanced directives; and concern for liability by medical professionals when confronted with the conflicting wishes of family members. Additional barriers include: the lack of accountability for professionals who fail to honor wishes; the frequent turnover of providers; inadequate discussion regarding advance directives; and the lack of an interdisciplinary approach to care.

## A suggested action plan emerged:

### Education

Educate using a uniform and interdisciplinary approach at all levels and in all venues.

- Advocate for educational opportunities for any individual who becomes a health care power of attorney.
- Change the current culture so that end-of-life issues become acceptable and easy to discuss.
- Encourage women's groups to include this issue as part of their agenda.
- Improve communication/discussion about the dying process, specifically discussions about honoring the individual's wishes.
- Educate consumers regarding the preparation of advance directives.
- Encourage end-of-life education in the school systems.
- Clarify the differences between a Do Not Resuscitate (DNR) orders, Health Care Power of Attorney (HCPOA) and advance directives.

### Policy

- Address liability for those who fail to honor the consumer wishes.
- Provide immunity for those who honor the legal wishes of the consumer.
- Develop uniform terminology and standards for advance directives.
- Encourage the National Association of Attorneys General to assist in developing and advocating for model legislation and national standards. This action is seen as necessary so that out-of-state advance directives are recognized.
- Provide protection for persons unable to express wishes; for example, persons with cognitive impairment.

### Provider

- Recognize that continuity of care is interrupted, in part, due to staff turnover.
- Require a reliable system of communicating consumer's wishes and/or any changes in those wishes to all providers, especially, on-call staff.
- Improve communication among all disciplines.