Choices for the Dying

End-of-life planning ensures that critical choices are left to you, and not someone else.

By Fran Moreland Johns

Dying, like old age, is not for sissies. Neither is it for the unprepared. Accidents, serious illness, or sudden injury can and do strike without warning, bringing people of all ages to the edge of death every day.

As the case of Terri Schiavo makes painfully clear, when a health crisis strikes, families and physicians are faced with agonizing choices about the treatment and ongoing care of an individual who can no longer share in the decision-making. While we all want to believe the person at our bedside will be someone who knows what we want and loves us enough to honor our wishes, in the emotional pressure cooker of a health crisis, even the most loving families can disagree. Physicians may offer conflicting advice; and government may soon take a role as well. For the sake of your family – and your own peace of mind – the way to insure you have the deciding voice in your own critical care is to leave clear, specific guidelines.

The key to individual choice at the end of life in situations of medical extremity is one document: The Advance Health Care Directive, outlining what you want for yourself. Advance directives can be as simple or as detailed as you choose. Their primary segments include designation of someone to make healthcare decisions for you if you should become incapacitated and an outline of your instructions for that care.

First, you designate an agent or healthcare proxy, formally called "Power of Attorney for Health Care." Most of us know deep down who we would most trust to direct our care if we could not. If you who want someone other than an immediate family member to manage your care, or if you know family members might disagree, formally naming your choice as healthcare proxy is a crucial element in allowing them to speak for you.

Secondly, in your Advance Directive you outline your wishes about life-sustaining medical treatments such as use of drugs and blood products, dialysis, respirators and surgeries. This is the portion commonly referred to as a "Living Will." You may also state your wishes about prolonging life with food and drink, and about levels of pain control. It's the absence of such a document that has caused years of family anguish in the case of Terri Schiavo and caused similar anguish a few years ago in the case of Nancy Cruzan.

Do you need an attorney to draw up your own advance directive? Not necessarily. Once the forms, available from hospitals, state and local medical associations and online are witnessed and, if required in your state, notarized, they are enforceable.

What you do need is simply to talk. Talk to your doctor, your family, clergy or spiritual advisors, close friends. Admittedly that's not an easy assignment. Most of us share a hesitancy to discuss dying-- our own or anyone else's-- until it's absolutely necessary. But that moment of necessity can come too late. Friends and family brought into such discussions early on are often grateful for the chance to share thoughts and preferences, and may even be encouraged to consider their own end-of-life planning.

Making your own decisions can also spare others unnecessary pain. Twenty years ago a young accident victim was kept alive, though comatose, for five months while his mother agonized over what he would want her to do. She made what for most mothers would be the only choice: to keep him alive, despite knowing he would never fully recover. He did emerge from the coma and lives now a severely handicapped life. His family still asks themselves: Did we do what he would want?

Although laws vary from state to state, once your wishes are properly made known providers generally follow their intent. The U.S. Living Will Registry maintains a site on which your document can be stored, accessible to hospitals throughout the country. Strict privacy measures guard this information from anyone else.

Most of us have strong opinions about what we would or would not want if we were suddenly incapacitated, and they may be wildly different from what others would choose on our behalf. Perhaps you would want to donate an organ if it would save a life, but not if it would only be used for research. Perhaps, facing a long and difficult terminal illness, you would want to hasten death by having food and/or water withheld while you are medicated for pain. Perhaps

you want to be kept alive in any way possible and for as long as possible, no matter what.

A Georgia physician tells the story of a dying mother begging to have a feeding tube removed while her husband and children were unable to agree about honoring this request. "It was," the doctor says, "the most difficult death I have attended in years. When she was gone, the family was hopelessly estranged."

To spare your family similar grief, and to have your own say:

- Talk with those important to you about what you want.

- Write it down.

- Have it witnessed and notarized.

- Circulate copies to your doctor, family members and those you love, and to anyone else concerned. Many people also keep copies in glove compartments, briefcases, and computer files.

The first of those points listed above tops the list for a reason: the most important factor in how critical care is handled is your relationship with your physicians. If you have told them your preferences, and written them down, end-of-life choices become your own rather than someone else's.

Over 80% of all deaths in the U.S. now occur in hospitals or related institutions, with a large majority of those deaths involving "negotiation"-- i.e., discussions between doctors and family members concerning treatment or the withholding of treatment. Whatever your age or state of health, the time to have your own say about your own body will never be better than right now.

Fran Moreland Johns, author of 'Dying Unafraid,' writes often on end-of-life issues for print and online publications. She is current board president of Compassion in Dying/N.CA and a member of the steering committee of the San Francisco Bay Area Network for End of Life Care.