

When Personal Decisions Become Political Battlegrounds



Lessons Learned From the Schiavo Family Tragedy

Sandy Padwo Rogers

The much publicized legal battle over the fate of Terri Schiavo, the brain-damaged Florida woman who became the latest national symbol of the end-of-life debate, should serve as a wake-up call to all of us to let our loved ones know our wishes should the unthinkable happen. This is never an easy discussion. For family caregivers, however, it is made all the more critical by the very nature of your role. What would happen to your loved one should you become incapacitated? Who will make crucial life and death decisions for you if you are unable to communicate your wishes? Family caregivers devote each and every day to taking care of the needs of the one they love. Who can you count on to be there for you should you need it?

Regardless of which side of the debate Americans were on regarding the removal of Terri Schiavo's feeding tube, we were united in our belief that had Terri made her wishes known to family and friends, many years of painful litigation and heart-break may have been avoided. What would she have had to do to communicate her wishes in a way that was clear to everyone involved? Legally, the answer is rather simple. A living will and a durable power of attorney for health care, also known as a health care agent or proxy, are two legal documents that make up what is often referred to as an advance directive.

A living will outlines what medical treatment you are willing to accept in the case of a terminal illness. A durable power of attorney for health care is used to appoint an individual to make healthcare deci-

sions for you should you become unable to do so yourself. As a family caregiver, you are likely the designated decision-maker for your loved one. Have you chosen someone to serve in that role for you? If the answer to that question is "no," it's time to make that choice. This person should be someone you trust to follow your wishes with regard to medical treatment decisions. Aside from sharing your wishes with this designated individual, it's important to make your views about future treatment options known to other family members and friends. Voicing your wishes now will help those you love avoid uncertainty later.

The paperwork you need to complete an advance directive is rather simple, and does not need to be handled by an attorney. Your local hospital or your state's attorney

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general's office will have the necessary forms. In addition, the National Hospice and Palliative Care Organization (NHPCO) provides state-specific advance directive documents and instructions via its Web site, www.nhpc.org. You may call the organization's help line at 800/658-8898 and the appropriate forms will be mailed to you.

Despite the relative accessibility of these documents, NHPCO estimates that less than 20 percent of all Americans currently have advance directives. The reason for this seems quite evident: It is a subject that no one wants to contemplate, especially those who have devoted themselves to caring for someone else. To help you begin these discussions, NHPCO also makes available two very useful brochures: "Communicating Your End of Life Wishes" and "Let's Start Talking" are both designed to help you talk about and share your wishes with family and friends.

Ensure Your Voice Is Heard

There is only one way to ensure that your wishes are honored if you can

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no longer speak for yourself. Making sure that family, friends, and your healthcare providers know that you have planned ahead will help them make the right choices for you.

While it is important to verbalize your wishes, it's even more important to have the proper paperwork in order, with copies available for distribution, so that any ambiguity is avoided. Upon any hospital admission, you will be asked for a copy of these documents. Make sure they are complete, signed by you and at least two witnesses, and dated.

Advance Directive

The complete set of documents you prepare to inform your physician and family members what kind of care you wish to receive in the event that you can no longer make your own medical decisions. These documents may also designate an individual to act on your behalf if you are unable to voice your own decisions regarding your healthcare. They should be updated whenever there is a major life event (marriage, divorce, etc.) or at least every 10 years.

Durable Power of Attorney for Health Care

Part of an advance directive, a durable power of attorney for health care, also known as a health care agent or proxy, designates an individual you have chosen to access your medical information and make decisions about your medical care if you are unable to speak for yourself. A health care agent can be assigned as part of your advance directive. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) has made it more difficult for doctors and hospitals to release your personal medical information without your written consent. Make sure that any form you sign designating an individual as your health care

agent also allows that individual to access your medical records. You may want to sign a separate HIPAA authorization form just to be safe.

Living Will

A living will is one component of an advance directive. It outlines what kind of medical treatment you want in certain situations. It only comes into effect if you are diagnosed with a terminal illness and have less than six months to live, or if you are in a persistent vegetative state. A living will does not, in and of itself, allow you to name someone to make decisions on your behalf.

Do-Not-Resuscitate Order (DNR)

Do you want resuscitation (efforts to restart the heart after it has stopped) to occur regardless of your medical circumstances? How do you feel about ventilators and other life-sustaining equipment? A DNR outlines what you will and won't accept when it comes to the use of medical technology to sustain your life. A DNR form can be part of your advance directive.

There is nothing more heart-breaking than seeing a family torn apart at a time when family members should be coming together for mutual support and understanding. No one wants to admit that a life-altering event can happen without warning. Family caregivers know better than most how circumstances can change in an instant, with no time to prepare or communicate with those you love. The greatest gift you can provide to your family and friends is to help them avoid the uncertainty, guilt, and conflict that may arise should the caregiver become the care recipient. ■

Sandy Padwo Rogers is the managing editor of TAKE CARE!