Advance Directives: A Call to Action

For weeks we listened to the media reports regarding the determination of the life of Terri Schiavo. We listened as the saga unfolded around the ethical and legal issues regarding the determination of her care. As a nurse, I was asked many times what I thought about the case. Over and over, I could only say, “I do not know.” I really did not know her state of being (physical, psychological, spiritual), I did not know her or her family, I did not know what Terri wanted. I could not and would not make a judgment about the ethical and moral issues of this case because I did not know, nor was it my place to say. I do believe, however, that the case of Ms. Schiavo is a call to action for all adults to act on giving direction to their end-of-life experience through advance directives.

Don’t Delay

Several lessons can be learned from the Terri Schiavo case. One is the fact that end-of-life directives should not be delayed until our elder years. Clearly, life-threatening tragedies are less common among young adults, but they do happen. Thinking about one’s own death at a young age is certainly not commonplace. Knowing and understanding the medical aspects involved in making end-of-life choices is even more complex. However, Ms. Schiavo’s case points out that youth is not free from tragedy. Ms. Schiavo’s situation has prompted me to speak to my adult children and their spouses about advance directives. I intend to take it further. I intend to discuss this issue with my nieces, nephews, siblings, and their spouses to encourage them to be proactive in outlining their preferences for end-of-life care. I want them to understand the importance of taking an active part in their care even if they are in a medical state that does not allow them to dictate their care at the moment. I also want them to know how important advance directives are to the family. In a time of stress, families are faced with the burden of making care decisions as they are trying to cope with the potential loss of a loved one. Directives from that loved one will make it easier to make decisions.

Obviously I have some work to do to see that my family and friends understand the value of completing advance directives. They will need to know that they have a right to make health care decisions, even about end-of-life care. They need to know that there are two types of advance directives: instructive and proxy. Instructive directives allow the individual to identify preferences for care in the context of some broad medical scenarios (for example, terminal illness, permanent coma, vegetative state). Living wills are the most common type of instructive directives. A durable power of attorney for health care is the most common type of proxy directive. This power of attorney allows the designation of a surrogate medical decision maker of the patient’s choosing. The individual with the designated power of attorney will only act in the event that the patient is incapacitated (physically, mentally, or both) (University of Washington School of Medicine, 1999).

Defining Life-Sustaining Care

Another lesson learned from the Terri Schiavo case centers on the issue of what constitutes life-sustaining care. Although the legal arguments focused on who had the right to determine Ms. Schiavo’s care, the ethical issue of withdrawing hydration and nutrition came to the forefront. The National Cancer Institute (2000) suggests that life-sustaining care modalities should be taken into consideration when drafting a living will. These include:

- The use of life-sustaining equipment (dialysis machines, ventilators, and respirators).
- “Do not resuscitate” (DNR) orders (instructions not to use CPR if breathing or heartbeat stops).
- Artificial hydration and nutrition (tube feedings).
- Withholding food and fluids.
- Palliative/comfort care.
- Organ and tissue donation.

To begin to make decisions about life-sustaining measures, an individual must try to understand scenarios wherein the measures could be applied. For example, a terminally ill patient codes following the use of contrast dye for a diagnostic procedure. Following the general intentions of the patient, the

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proxy elects not to have hydration and nutrition provided via tube feedings. In a severe head trauma situation, the patient’s outcome may not be known for some time; thus, a feeding tube is inserted. Again following the general intentions of the patient, the proxy allowed that feeding tube to be inserted. At a later time, however, the proxy requests that the feeding tube be withdrawn to follow the patient’s wishes of no food or hydration if the patient were in a persistent vegetative state.

As a medical-surgical nurse with oncology experience, I am most aware of the issue of pain management for comfort. My proxy understands that I prefer to have pain medication titrated for my comfort regardless of the fact that it may decrease my respirations. Without some framework to understand the use of life-sustaining measures, an individual cannot make informed decisions. Nurses play an important role in helping people understand potential common scenarios. Although no scenario can truly exemplify the reality of an end-of-life situation, it can provide parameters for medical care should such a situation occur.

**Nursing Advocacy**

Finally, the Terry Schiavo case highlighted the advocacy role of medical-surgical nurses in educating our families, friends, and communities about the importance of advance directives. We can do this in many ways. Clearly direct communication with family members is important. We can serve as models to family and friends as we share the fact that we have advance directives and possibly identify some areas that were important discussion topics as we completed those directives. We can also educate the community by giving presentations to community groups such as parent-teacher organizations and church groups. We can write brief articles for community newspapers or local newsletters. In our communication activities, we can provide resources for information for advance directives. Selected Internet resources can provide information about advance directives, including those referenced in this article. Some sources offer templates for health care directives (for example, Law Depot: http://www.lawdepot.com/contracts/healthdir/?ldcn=healthdir&pid=google-health_us-dir). Ultimately, we need to use our resources and creative energies to encourage members of our community to complete advance directives.

It is unfortunate for Ms. Schiavo and her family that her end-of-life situation became such a public issue. However, we can take the public’s awareness of the situation as an opportunity to stress the importance of end-of-life care and encourage adults to complete advance directives.

**References**
