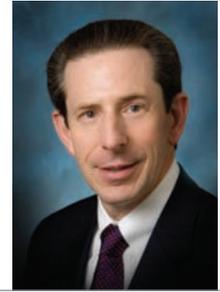




# ADVANCE DIRECTIVES: SINCE SCHIAVO, MORE IMPORTANT THAN EVER

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The media attention surrounding Terri Schiavo during 2005 caused an intense national debate on the ethical, moral, and legal issues relating to end of life decision making. In flurries of activity rarely seen in legislative bodies, both the Florida legislature and the United States Congress took the extraordinary steps of passing special legislation in their efforts to keep Ms. Schiavo alive.

This of course refers to the Florida woman whose brain was deprived of oxygen for seven minutes after her heart stopped due to an undiagnosed potassium deficiency. Physicians later concluded that she was in a persistent vegetative state, leaving her to rely on tubes for food and hydration. After her husband decided to have caregivers cease providing her with food and hydration, her parents began a legal battle to stop the withdrawal of food and hydration in order to keep her alive.

While public opinion was widely divided on the issues presented in this struggle, there are two points that most healthcare providers can agree upon. First, this controversy could just as easily have arisen from treatment of a patient at a local community hospital such as Lancaster General Hospital as from a patient in a Florida hospice. Second, this controversy could have been avoided if Ms. Schiavo had executed an advance directive. Because Ms. Schiavo had no advance directive, the media focused debate was about the type of healthcare others thought Terri Schiavo should receive instead of the type of healthcare Terri Schiavo would have wanted for herself.

Physicians and hospitals all over the country deal with end of life decisions for their patients every day. Since an estimated 75-85% of the population have not executed advance directives, it is no surprise that healthcare providers from time to time deal with incompetent patients in either a terminal condition or a permanent state of unconsciousness (including a persistent vegetative state or permanent coma), who do not have an advance directive, and whose close family members cannot agree on a plan of care. Fortunately, all of these circumstances are resolved in some fashion without

acts of Congress or state legislatures, and usually without the interventions of courts.

In order to put the Schiavo case in an appropriate framework, we should re-visit the basics of patient decision making. First, every competent patient is entitled to make decisions on the care they do or do not want to have. This is true even if we believe patients are making “bad” decisions or decisions against medical advice. Second, when the patient is incompetent to speak on his or her own behalf, either because of mental or physical incapacity, the patient does not lose the right to make decisions regarding their medical care. We look to a source other than the patient to make those decisions on behalf of the patient. That source may be a guardian appointed by a court to act on behalf of the patient. If there is no guardian, that source may be a written document such as a living will or a Durable Family Power of Attorney. A living will is a document which describes a patient’s wishes for care if he or she is incompetent, and either is in a terminal condition or a permanent state of unconsciousness. A Durable Family Power of Attorney is a document that designates another individual to make decisions on behalf of an individual if that individual can no longer do so on their own. When there is no written document to guide us, we look to close relatives, usually in the order of spouse, children, parents and siblings. Third, when we look to close relatives to make decisions, they are supposed to make the decision in the context of what the patient would have wanted if he or she could make the decision, not what the relative would want.

In the context of the Schiavo litigation, there was no advance directive. Therefore, the courts focused on whether Ms. Schiavo had ever told anyone what her desires for care would be if care would only prolong the process of death, or if she was in a persistent vegetative state. This gave rise to the opportunity for disagreement between the husband and parents. There would have been no basis for disagreement if there had been an advance directive in which Ms. Schiavo had set forth her desires for care.

There are many reasons why we should encourage patients to consider an advance directive. Most importantly, it is the right thing for the patient. It is an opportunity for patients to express to their healthcare providers their desires for care so that the healthcare providers can respond appropriately. In addition, the presence of an advance directive will reduce disagreement among close family members about an appropriate approach to treatment, since the patient has already provided guidance. Further, an advance directive will make the job of the healthcare providers easier in both developing an appropriate treatment plan in keeping with the patient's wishes, and in dealing with family members. Finally, an advance directive takes much of the burden of decision making off of family members at a time that can be highly emotional.

When speaking with patients about advance directives, these are the points that should be emphasized:

1. The best way to assure that the care you desire in an end of life situation is implemented is to put it in writing through the use of an advance directive.
2. Even if you have an advance directive, as long as you are competent and can communicate with your physician, you can continue to tell the physician directly what care you want.
3. Advance directives are effective only if you are unable to communicate on your own, and if either your physician determines you are in a terminal condition, or you are in a state of permanent unconsciousness.
4. If you have an advance directive, DO NOT store it in a safe deposit box at a bank or a similar secure place. Instead, tell your next of kin that you have an advance directive, and give copies to your next of kin, your primary care physician, a specialist physician you see frequently, and your hospital. Have healthcare providers place the copy in their medical records. Advise patients to have frank discussions with next of kin about their desires for care if they were to have a terminal condition or were in a state of permanent unconsciousness. If the first time family members find out that their loved one has a living will is when their loved one has a serious illness, they may be surprised and less accepting of the decisions set forth in the living will. However, if family members have been advised that their loved one has an advance directive, and there is a discussion about their loved one's wishes for care when he or she has a terminal condition or is in a state of permanent unconsciousness, family members will be more likely to honor the loved one's wishes when the time comes.

5. Advance directives are not just for old and sick people. Young people just like Terri Schiavo can benefit from an advance directive.

Physicians, hospitals, and other healthcare providers should consider their legal and ethical obligations when presented with a patient who has an operative living will (i.e., the patient is not competent, and has a terminal condition or is in a state of permanent unconsciousness). From time to time we hear of anecdotes from nurses or others in which a physician ignores the provisions of a living will and instead takes contrary direction from family members who want extraordinary means used to extend the life of their relative. The motivations of physicians to ignore the provisions of a living will in these circumstances probably vary. The most likely motivation is the fear of being sued by family members. Physicians may fear that the family members will sue the doctor for malpractice, wrongful death, or on some other theory if their directions are not followed. Another motivation is likely to take the "path of least resistance". Physicians may feel it is simply easier to act in accordance with the wishes of highly emotional family members than to ignore family members by following the directions in a living will for a patient who cannot speak for him or her self, and is either dying or in a state of permanent unconsciousness.

The legal and ethical obligation of physicians in this situation is clear. Physicians have an ethical duty to act in accordance with the wishes of their patients. Physicians have no more right to ignore the valid instructions of an incompetent patient contained in a living will than they have to ignore the instructions of a competent patient in favor of contradictory instructions from the patient's family members. Further, the Pennsylvania statute authorizing living wills (or declarations, as they are referred to in the statute) provides that when a living will becomes operative (i.e., the patient is incompetent, the patient either has a terminal condition or is in a permanent state of unconsciousness, and the physician is presented with the living will), then "the attending physician and other healthcare providers shall act in accordance with its provisions...". The only statutory exception is for physicians who cannot in good conscience comply with a living will, or the policies of a healthcare provider preclude compliance with a living will. In that circumstance, the physician must inform the patient or the patient's family, guardian or other representative, and make every reasonable effort to assist in the transfer of the patient to another physician or healthcare provider who will comply with the living will.

Fear of being sued by the patient's family members is more of a perceived threat than an actual threat. Pennsylvania law provides physicians and other healthcare providers with immunity from civil, criminal or administrative prosecution for following a patient's wishes as expressed in an advance directive. The law states that a healthcare provider who causes or participates in the initiating, continuing, withholding or withdrawal of life sustaining treatment from an incompetent patient shall not be subject to criminal or civil liability, or found to have committed an act of unprofessional conduct, if the attending physician has followed the patient's wishes as expressed in an advance directive. Therefore, it is unlikely that a family member could institute litigation against any healthcare provider for following the directions in a living will, and if litigation was brought, the immunity provisions of Pennsylvania would apply.

The presence of an advance directive is not a guarantee that the care of a patient will be free from controversy, but it is

likely to go a long way to removing any uncertainty about the patient's wishes in end of life situations. The standard Pennsylvania form of advance directive can be downloaded from the internet, or a copy can be obtained from most hospitals. This form of declaration is suitable for most patients, but patients may use other forms of a declaration.

The Terri Schiavo case has opened the door for healthcare providers to speak frankly with patients about living wills. While many people do not like to consider matters relating to death and dying, more people than ever before are interested in living wills due to the national debate created by the Schiavo case. These are decisions better thought through when removed from the immediacy and emotionality of the end of life. Helping our patients to explore these issues now will benefit both the patients and the healthcare providers who will be providing care when these decisions will be necessary.

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