Don't Wait to Make Your End-of-Life Wishes Known

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The recent Schiavo case in Florida--the battle over whether or not to remove an unconscious woman's feeding tube--is not a "right to die" case. It's not about whether she should be able to remove the tube; it's about whether she wants to.

How best to respect an unconscious patient's wishes in end-of-life decision-making is actually a matter on which there is great hope for public consensus. Secular and biblically-oriented people, for instance, typically take a rather similar approach to the question of who should decide, even when they differ sharply over what that decision should be. All alike tend to maintain that the decision belongs to the patient.

This commentary will first explain why there is such agreement. Then it will explain what this means for situations where patients are unconscious or otherwise unavailable to express their wishes. Finally, it will explain how potential patients and loved ones of potential patients--in other words, all of us--should be preparing now to make possibly unavoidable decisions well.

Why the patient's wishes matter. In today's "postmodern" age, many consider the idea of an objective reality, especially any objective moral truth applicable to everyone, to be an illusion. Accordingly, we are to respect people's own perspective on life and decision-making. Allowing patients to make their own end-of-life decisions fits perfectly within such an outlook.

People with a more biblical worldview are more apt to affirm that there are standards of right and wrong applicable to everyone, and that some decisions are better than others on moral grounds. But they, too, recognize that vital decisions such as whether or not to begin a potentially life-sustaining treatment belong ultimately to individuals themselves (preferably with counsel and support from others). People may make wrong decisions--decisions contrary to God's intentions for human well-being--but people should be allowed to bear the responsibility and consequences of making those decisions, as long as they do not substantially harm others in the process.
The biblical call to "choose life" (Deuteronomy 30) echoes throughout the Bible in a holistic way. It challenges people to choose the abundant spiritual life offered to those who trust God. And it challenges people to make life-affirming rather than death-seeking decisions in terms of medical care. But it is about "choosing" as much as it is about "life." God loves us so much that we are given the opportunity and responsibility to make vital decisions, whether we make them rightly, in life-affirming ways, or wrongly.

When the patient can't communicate. Sadly, people do not always have the mental capacity to make medical treatment decisions when they must be made--for example, patients who are unconscious or quite confused. Since decisions even then should be in accordance with the patient's wishes, the key issue becomes whether or not the patient has expressed those wishes in advance.

We human beings typically don't like to talk with others about our own death. We hate to picture ourselves gone--or even worse, going through a difficult dying process. Ironically, by not planning ahead, we can make our dying process even more prolonged and difficult! Our loved ones may be left to agonize over what treatments to start or continue, and all too often in their reluctance to let go they will put us through predictably useless interventions that only add burden to the dying process.

Patients and loved ones alike suffer, then, when the latter are left to guess at the patient's wishes regarding significant medical treatment decisions. People have a big stake in making sure that their wishes are clearly known in advance by their loved ones. And loved ones have a big stake in making sure that everyone for whom they might have to make health care decisions has clearly communicated to them his or her wishes.

Who should be included in this circle of decision-makers? While parents typically decide for children and adult children sometimes decide for elderly parents, decision-makers are most often patients' spouses. Normally a spouse--or a particularly close companion or friend for an unmarried adult--is in the best position to know and advocate a patient's wishes.

However, the Schiavo case underscores the need for legal review in exceptional cases, where there is significant evidence that money or other personal temptations hinder a spouse's ability to advocate for the patient without bias. Every case is unique, and patients themselves generally know best who will represent their wishes most faithfully. They do their family or other loved ones a great service by clarifying who should make such decisions (and, by implication, who should not).

How you can plan ahead. Once people recognize the importance of making their medical treatment wishes known in advance--or their loved ones recognize it for them--what can they do? One important option is writing an advance directive.
An advance directive simply gives directions to caregivers in advance. It may include a durable power of attorney for health care ("durable power" for short), which specifies who is to make decisions on behalf of the patient should the patient loses the capacity to do so. It may include a living will, which provides whatever information the patient wants to provide to guide such decisions. In many cases, it includes both.

The living will is the oldest and most familiar form of advance directive. Many people are rightly uncomfortable with it when it is used alone, without a durable power. The reason is that any directions patients can give about the type of treatments they want or (more commonly) don't want in life-threatening situations are unavoidably general. They may not accurately represent patients' wishes in exceptional cases. They may open the door to unwanted premature death--though confusion can lead to overtreatment instead.

Many wisely prioritize the durable power as the more important provision of an advance directive. It can virtually ensure that there will be a live decision-maker present to represent the patient's wishes in the particular situation where decisions for the patient must be made. There are three reasons why people's advance directives sometimes do not accomplish this goal, even when they contain a durable power.

First, sometimes only one person is given the decision-making power. However, decision-makers can be incapacitated by the same accident as injured the patient, or can be unable or unavailable to represent the patient's wishes for many other reasons. Durable power documents should therefore appoint a back-up decision-maker, or even more than one if the first two decision-makers might well be unavailable at the same time.

Second, a person sometimes appoints decision-makers without notifying them or discussing his or her treatment wishes with them. Those appointed may be fine people, but if they do not specifically know what the person wants, they cannot ensure that decisions made actually honor that person's wishes. Moreover, if they do not even know that they have been appointed, they may not take the initiative necessary to become immediately available for decision-making when they hear that the person's mental ability has been compromised.

Third, people's advance directives may contain both living will and durable power sections, but lack any explicit indication as to which takes priority over the other. This is perhaps the most common omission in advance directives. Including living will guidance for caregivers in advance directives is fine--it can help remind decision-makers of what matters most to patients. However, advance directives must specify that such guidance can be disregarded when (and only when) the appointed decision-maker deems that following it would result in an action contrary to the patient's wishes--for example, in unanticipated exceptional situations. Otherwise, advance directives can create the same problem that living wills alone cause, when no durable power is included. Advance directives should give those with decision-making power the explicit authority to interpret living will provisions if clarification is needed.

**A Practical Next Step You Can Take:** [Download Advance Directive Form with Instructions (PDF)]