BY THOMAS J. MURPHY

Drafting Living Wills After Schiavo

For estate planning practitioners, the Terri Schiavo controversy has created a "good news, bad news" situation. The good news is that the *Schiavo* case heightened interest in the general public regarding the need to have a living will, also known as an advance medical directive. The bad news is that *Schiavo* poses a tougher challenge for practitioners by highlighting the need to draft living wills that address the problematic issues that arise when family members cannot agree on treatment for a seriously ill person.

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In light of that case, Arizona practitioners must learn to include new provisions in the living wills they draft for their clients.

The *Schiavo* case first came to public attention in the spring of 2004 when the Florida legislature passed a statute that precluded Ms Schiavo's husband/guardian from withdrawing life support procedures. Since that time, I have reviewed hundreds of living will forms and have discussed the matter with many health care providers and administrators as well as other attorneys.

There are three deficiencies that I commonly see in the living wills—including my own—that I have reviewed. First, they often only apply to a patient who has been diagnosed as terminally ill. However, many patients, including Terri Schiavo, may be gravely ill and in an irreversible condition but are not considered to be terminally ill.

Second, virtually all living wills are premised on the fact that all family members know what the patient would want to have done and are all in agreement on this. But when a dispute erupts, as in *Schiavo*, living wills are silent on how to address and resolve this.

Third, living wills typically offer very little practical or precise guidance to the decision-makers beyond some general platitudes about undertaking no heroic measures. With many state legislatures proposing tighter standards for ascertaining the patient's intentions, providing some guidance will take on added importance.

Given these concerns, here are some suggestions for drafting more effective living wills.

Terminal and Non-Terminal Conditions as the Triggering Event

Most living wills specifically apply to a terminally ill patient. But often the term "terminally ill" is not defined, which can create problems for health care providers. The most workable option is to use the Medicare definition of "terminally ill," defined as death occurring within six months of the diagnosis if the condition runs its normal course.[1]

But this does not solve all the problems. Several gerontologists have emphasized to me that patients with advanced

Alzheimer's or who have suffered a serious stroke are never considered to be terminal. It would also not include those patients in an irreversible coma or persistent vegetative state, or those patients who may be conscious but enduring an unacceptable quality of life due to the injury or illness.

As a result, I have revised my living will to address three categories of conditions that will allow the agent or agents to make the decision regarding end-of-life care:

a. an incapacitated person who is terminally ill,
b. irreversible coma, brain death or persistent vegetative state and
c. a greatly diminished and hence unacceptable quality of life.

The first category is for the incapacitated terminally ill patient. I use the Title 14 (probate code) definition of incapacity: the inability to make or communicate responsible decisions about the person.[2]

The second category of a patient's condition is for an irreversible coma, brain death or persistent vegetative state ("PVS"). Terri Schiavo would have come within this category. Because of the media coverage of Ms. Schiavo, several clients have already questioned me about the appropriateness of using PVS as a standard, because much of the media raised questions about what a PVS diagnosis meant and even if such a condition actually exists.

Unfortunately, much of this media discussion was very inaccurate and misinformed. Since the early 1990s, PVS has come to be a well defined and recognized condition. The leading authority is the Multi-Society Task Force on PVS that issued a two-part article in 1994 in the *New England Journal of Medicine* that set forth the definition and clinical aspects of PVS.[3] A diagnosis of PVS requires no awareness of self or the environment and an inability to respond to any visual, auditory, tactile or noxious stimuli. The distinguishing feature is intermittent sleep–wake cycles in which the patient opens his or her eyes with some reflexive response to external stimuli. But the response is only reflexive. There is no sustained visual tracking of an object or any fixation on a visual target. Likewise, other reflective actions such as gagging, coughing, chewing, blinking, smiling, grimacing or sighing may occur. Most PVS patients have fairly normal breathing and gastrointestinal functions and maintain a normal body temperature but are unable to experience pain, thirst or hunger.

There seem to be two main points to emphasize to a client who may have some reservations about appointing an agent if the client should ever lapse into PVS. One point is that the diagnosis can only be made if the patient lacks all awareness. The second point is that at least one month must elapse since the onset of the condition before a diagnosis of PVS can be made. In other words, a doctor cannot make this diagnosis within hours or days of admission to a hospital. This has been a frequent concern of my clients since *Schiavo*.

The third category of a patient's condition that will authorize an agent to act is if the non-terminal patient is incapacitated and suffering an unacceptable quality of life. The patient may be conscious and somewhat alert, but the illness or injury has caused the patient's condition to deteriorate to the point where life may no longer be worth living. This category would include the advanced Alzheimer's patient or the patient who has suffered serious and irreparable injury from a stroke.

Guidance to the Agent/Decision-Maker

It is difficult for many clients to define or describe exactly when it becomes fruitless to continue treatment and accept a death occurring sooner than it otherwise might. It is also impossible to plan for every medical treatment or possibility.[4]

This is where estate planning practitioners will need to get creative and even seek assistance of the medical community in drafting living wills. Most living wills are couched in terms of treatments, or what the medical community calls "interventions." The typical living will has the client check off yes/no boxes dealing with specific interventions like CPR, dialysis, transfusions or chemotherapy. But this is just a tiny portion of all possible interventions. What of the other thousands of interventions or future interventions not yet invented or widely used?

The doctors with whom I have spoken strongly discourage this approach. Instead, they recommend a broad, goal-oriented approach.[5] It focuses on the result the patient wants to achieve and not on how to reach that result. My new, revised living will lists the following criteria for the agent to consider when making a decision:

- Inability to walk without the assistance of others or a wheelchair
- Experiencing pain most of the time
- Experiencing discomfort (such as nausea, diarrhea or weakness) most of the time
- Inability to control my bladder and bowels
- Having a feeding tube inserted into my stomach and/or being unable to be fed by a spoon
- Use of a ventilator that is required to keep me alive
- Inability to recognize family or close friends
- Incurring costs for the provision of medical care that will create a financial hardship for me, my family or other loved ones

The idea is to provide some objective guidance to the decision-maker. The living will should indicate that any one or more of these criteria tend to support the decision to withhold or terminate life support. In other words, the decision-maker is not compelled to withhold life support if one or more of the criteria exist. Rather, they are simply factors for the agent to weigh when exercising his or her discretion.

When I began to use this approach, I was surprised by my clients' reaction. Some wanted to include some of these criteria but not all. Different clients removed different criteria. As a result, I have the client initial those with which they agree. I am also considering having a blank space next to each criteria and having the client use a scale of 1 to 5 to rank them in order of importance.

This is far preferable to the approach often taken by practitioners that simply authorize the withdrawal of life support treatment if the burdens of treatment outweigh the benefits. Such an imprecise test is an invitation to litigation if a dispute within the family erupts. It will also create problems in those states where legislation may be enacted to impose higher standards in proving the patient's intentions.

Schiavo emphasizes the need to provide the decision-maker with some delineated and objective criteria to consider when making the decision. This is not an easy task for the estate planning practitioner who is discussing this with a young and healthy client who has never given much thought to any of this. A goal-oriented approach has worked well for me.

Disputes Regarding the Withdrawal of Life Support

Another difficult issue in the *Schiavo* case was the dispute that erupted regarding decisions made by Ms Schiavo's husband/guardian. Virtually every doctor or hospital administrator with whom I have spoken has candidly admitted that it is the family member who complains the loudest who will, at least initially, control the decision regarding termination of life support treatment. In other words, a hospital ethics committee will not authorize the withdrawal of life support if there is a family member who is threatening to hire a lawyer or complain to a local television reporter. While estate planning practitioners can argue over whether a hospital can lawfully exercise such authority, it is a foreseeable situation that must be addressed when drafting a living will.[6]

I have made three revisions to my living wills to address disputes. First, I have included a new paragraph captioned "Resolution of Disputes" that names a particular person to make the final and binding decision in the event of a disagreement.

Second, in that same paragraph, there is a provision that names who is excluded from the decision-making process, such as a troublesome child or in-law. This is to avoid what one colleague of mine has characterized as "the black hat on the white horse," such as the child who has not been in contact with the family for many years but who suddenly appears and wants to control the decision. This provision should prevent this messy situation from affecting the decision.

Third, I have added a paragraph that specifically allows the agent to initiate litigation against the hospital, health care provider or family member who fails to promptly implement the agent/decision-maker's directives. This is already authorized under the Patient Self Determination Act,[7] but it is always a good practice to include this language because this could be the tipping point in having the hospital honor the agent's decision.

Likewise, a provision should be added that the patient or the patient's estate will not be responsible for the payment of medical bills for services provided that are inconsistent with the patient's desires. Although this provision may not be enforceable, it may cause doctors and family members to think twice when the decision is made. Or a provision may state that any family member will forfeit his or her inheritance if they contest, interfere with or delay the patient's expressed desires.

Other Suggestions

Several other points should be kept in mind when drafting living wills.

First, all practitioners should reacquaint themselves with the seminal United States Supreme Court decision in *Cruzan v. Director, Missouri Dep't of Health,*[8] which held that there is a constitutionally protected right to refuse any and all health care treatment, including the provision of nutrition and hydration. A state is permitted to require a surrogate decision-maker to produce clear and convincing evidence of what the patient's desires would have been, but it cannot otherwise infringe on that right.

Arizona law[9] and the federal Patient Self Determination Act, which largely codified the *Cruzan* case, require that all health care facilities must follow a living will or other advance medical directive. These authorities should remind practitioners that they should not be constrained by restrictive state laws. This is not a problem in Arizona, where a statutory form is suggested but not required.[10] However, a practitioner can never be sure where the living will may be exercised. Examples of overly restrictive state laws are where a state requires the use of a statutorily created form, limits the decision-making authority to only certain irreversible or terminal conditions or to a certain period of time, requires a doctor's certification or where the cessation of nutrition and hydration is prohibited. Practitioners should cite to Arizona statutes and indicate that the living will is in compliance with applicable Arizona law.

Another point to consider concerns the termination of the provision of hydration and nutrition. The media in *Schiavo* repeatedly referred to "starving her to death" and of the pain that would result to Ms. Schiavo. This is not so. Patients do not starve to death in these situations. It is the lack of hydration that results in death. Withholding hydration causes death much faster than withholding nutrition. The lack of hydration creates renal (kidney) failure that causes a fairly painless death, usually within days and always within a month of the withholding. It also overlooks that food or fluids can be very distressing to a dying patient by making it harder for the patient to breathe and increasing the need for suctioning. It can also increase pressure on tumors, thereby increasing pain. Food and fluids can also induce nausea, diarrhea or swelling.

It should also be kept in mind that most of the justices in *Cruzan* stated that artificially administered hydration and nutrition is a medical treatment. It

OTHER SOURCES

- It helps to have clients elaborate on their thoughts and goals for end-of-life issues by reviewing and completing a values questionnaire. There are a number of good questionnaires on the Web. Two of the best are the Values History Form published by the Institute for Ethics of the University of New Mexico Health Sciences Center, available at **http://hsc.unm.edu/ethics/advdir/vhform_eng.shtml** and the *Caring Conversations* questionnaire published by the Center for Practical Bioethics in Kansas City, available at **www.practicalbioethics.org/mbc-cc.htm.**

- Two useful sources for drafting living wills are the popular *Five Wishes* booklet that can be purchased for $5 from **www.agingwithdignity.org** and the *Lawyer's Tool Kit for Health Care Advance Planning* published by the ABA's Commission on Legal Problems of the Elderly, available at **www.abanet.org/elderly.**

- For a very compelling insider's view of a family's end-of-life ordeal, read *Long Goodbye: The Deaths of Nancy Cruzan,* an excellent book written by William H. Colby, attorney for the Cruzan family, available from **www.longgoodbye.org.**

requires consent by the patient or agent and a skilled clinician to implant and remove the feeding tube. There is nothing natural or non-invasive about it.

Encouraging Clients To Have "The Talk"

No written document can take the place of a thorough discussion among family members about end-of-life issues. The silver lining of *Schiavo* is that, hopefully, more of these discussions have occurred and will take place. Practitioners drafting living wills are simply trying to memorialize that discussion. The objective is to allow the agent/decision-maker to make the best decision they can with the least amount of guilt. The agent should be able to say, "That's what Dad would have wanted us to do." If that occurs, the drafting attorney has done an exemplary job.

endnotes

1. 42 C.F.R. 418.3.
2. A.R.S. § 14-5101(1).
3. Multi-Society Task Force on PVS, *Medical Aspects of the Persistent Vegetative State*. 330(21) NEW ENG. J. MED. 1499-1508 & 1572-1579 (May 26, 1994).
4. A. S. Brett, *Limitations of Listing Specific Medical Interventions in Advance Directives*. 266(6) J. AM. MED. ASS'N 825 (Aug. 14, 1991).
5. James A. Tulsky, *Beyond Advance Directives: Importance of Communication Skills at the End of Life*. 294(3) J. AM. MED. ASS'N 359-365 (July 20, 2005).
6. Alan Meisel, Lois Snyder, & Timothy Quill, *Seven Legal Barriers to End-of-Life Care: Myths, Realities and Grains of Truth*. 284(19) J. AM. MED. ASS'N 2495-2501 (Nov. 15, 2000).
7. 42 U.S.C. § 1395cc(a).
8. 497 U.S. 261 (1990).
9. A.R.S. § 36-3204.
10. *Id.* § 36-3224.