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SPECIAL REPORT: Obtaining or Refusing Treatment That Reflects The Client's Wishes

Hook Law Center Offices:
295 Bendix Road, Suite 170, Virginia Beach, Virginia 23452
5806 Harbour View Blvd., Suite 203, Suffolk, Virginia 23434
www.hooklawcenter.com

Tel: 757-399-7506
Fax: 757-397-1267
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Most of our older clients at some point confront the necessity of making critical health care decisions. Many of them have treatment preferences and want to avoid inappropriately aggressive healthcare during a terminal illness. How should these treatment preferences be implemented if the client is unable to make his or her own healthcare decisions? Unfortunately, to answer this question, our older clients must comply with a complex set of court decisions and laws. Elder Law attorneys are uniquely qualified to assist their older clients and their families when confronted with this difficult situation.

The United States Supreme Court in *Cruzan* held that the Fourteenth Amendment protects a person's "liberty interest in refusing unwanted medical treatment." This right to make medical treatment decisions has, however, been limited by countervailing state interests, such as: (1) protecting a minor child, (2) prevention of suicide, (3) considering the interests of innocent third parties, (4) preservation of life, and (5) maintaining the ethical integrity of the medical profession. A significant line of cases deals with the standards for healthcare decision making for a patient who is incapacitated. The courts acknowledged that incompetent people have the same rights as competent people, although their rights must be exercised by surrogates. Because of the involvement of the surrogate, the court held that (1) the states may establish procedural safeguards to protect the rights of incompetent people and (2) doing so does not violate the Fourteen Amendment.

In January 2005, the procedural requirements for surrogate healthcare decision making were again presented to the United States Supreme Court. This case concerned Terri Schiavo who was in a persistent vegetative state and did not leave written instructions concerning her healthcare if she became incapacitated. In 1993, Ms. Schiavo's parents and spouse disagreed on whether to remove her feeding tube. This disagreement resulted in a series of legal actions to challenge the husband's right to make healthcare decisions for her. These cases, including *Cruzan* and *Schiavo*, demonstrate the importance of setting out one's desires in a written advance directive and discussing these desires with your family.

Another controversy has arisen concerning the right of patients to obtain physician assistance in dying. The U.S. Supreme Court has held that there is no constitutional right to obtain physician assistance in dying. In 1997, an Oregon statute became effective authorizing physician assistance in dying. Since the statute became effective, over 170 terminally ill people have obtained physician assistance in dying. The statute has been upheld by the United States District Court for the District of Oregon and the United States Court of Appeals for the Ninth Circuit. On November 9, 2004, the Attorney General appealed these decisions to the United States Supreme Court. The United States Supreme Court announced on February 22, 2005 that it would hear oral arguments in the court term that begins in October of 2005.

While a surrogate healthcare decision maker can be a court-appointed guardian, an individual is far better served by executing an advance directive which can be in the form of a living will, medical power of attorney or a combination of these documents. A living will is an expression of how the individual wants to be treated during end of life care. The medical power of attorney is a delegation of authority to a third party to make healthcare decisions for the individual. All 50 states and the District of Columbia impose statutory requirements on the content and execution of these documents for them to be valid.

Should the individual use a medical power of attorney or living will? Some claim the use of living wills a failure because people lack the knowledge to make intelligent decisions in advance, and so their preferences are not adequately articulated in the living will. Others note that too often living wills are not accepted by third parties. A few states do not recognize living wills. In those states a living will is treated as a statement of the individual's values. However, for our older clients who have known existing conditions and strong preferences about the treatment of those conditions, Hook Law Center recommends a combination of a living will and medical powers of attorney. The living will needs to state the individual's preferences and the medical power of attorney to authorize the agent to implement those preferences. For those older clients who do not have known existing conditions or treatment preferences, Hook Law Center recommends only a medical power of attorney.

Many of our elderly clients will have existing conditions and treatment preferences for those conditions. Many people will want to address these conditions specifically in their advance medical directives. The majority of our older clients, however, will not have any advance directive, either form or customized. Others will have a known family member who will object to the treatment preferences. Statutory or other standard form advance medical directives will not be adequate for these clients. Clients who have existing conditions and treatment preferences for those conditions should specifically address those conditions in their advance medical directives.

When drafting an advance directive, start with the state statutory form, where available, because it will be recognized by healthcare practitioners. Then customize the statutory form to address the individual's particular concerns by assisting the individual to focus on his or her medical treatment preferences. The individual should be asked to consider:

- Who will serve as the healthcare agent and alternative agent?
- If co-agents are appointed, must they act jointly or may they act independently?
- Whether the individual has identified one or more persons who do not share the individual's values and who the individual desires to expressly deny any authority to make healthcare decisions for the individual?
- Under what conditions, if any, does the individual want to authorize the withdrawal of life-sustaining medical treatment?

- Does the individual's authorization to withhold or withdraw life-sustaining medical treatment extend to nourishment or hydration?
- Does the individual have a known physical ailment that should be described along with the treatments that the individual wants or rejects?
- Does the individual have any specific preferences concerning healthcare facilities or providers?
- Does the individual have any moral or religious convictions that dictate use or rejection of certain forms of medical treatment?
- Does the individual want to make anatomical gifts or give the agent the power and authority to make these gifts?
- Does the individual want to authorize the agent to determine who will visit the client?
- Does the individual want to obtain physician assistance with dying to the extent compatible with state law?

In light of the privacy rules in the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and related regulations, the advance directive should include a specific, immediate authorization under HIPAA for the individual's healthcare agent to obtain confidential information concerning the individual's mental and physical condition

The elder law attorney should discuss with the client how to make the existence of his or her advance directive known to the client's family and physicians. At a minimum, the older client should have a candid and frank discussion of the advance directive and his or her healthcare preferences with his or her immediate family, healthcare agent and primary care physician and provide all of them with copies. To assist the older client in initiating this discussion, the attorney may offer to mail a copy of the advance directive to the client's family, physician and healthcare agent. Where the client is having a difficult time discussing his healthcare with his or her family, the attorney may wish to lend a copy of *The Long Good Bye: The Deaths of Nancy Cruzan* the client to read. The book is an excellent tool to demonstrate the importance of having an advance directive and it will facilitate intra family discussions of the client's wishes.

Some attorneys may provide their clients with a laminated wallet card that informs third parties of the existence of the advance directive and the names and telephone numbers of the client's healthcare agents. The attorney may also want to advise the client about commercial advance directive registries that will store the client's advance directive and, if the client is hospitalized, fax a copy of the advance directive to the hospital.

ABOUT THIS HANDOUT

This guide is provided as a courtesy to help you recognize potential estate planning issues. It is not intended as a substitute for legal advice. It is distributed with the understanding that if you need legal advice, you will seek the services of a competent elder law attorney. While every precaution has been taken to make this

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