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YOUR "LIVING WILL" MAY NOT WORK WHEN YOU NEED IT MOST
FIXING FIVE FUNDAMENTAL FLAWS

FAMILY MATTERS TURNED INTO NATIONAL HEADLINES. Remember Terri Schiavo? Mrs. Schiavo died in 2005, after having been in a "persistent vegetative state" for fifteen years. She was essentially "brain dead." In one of the longest litigations ever, courts struggled with the issue of whether or not she should be kept "alive" by giving her non-oral nutrition (tube feeding).

You may agree with Mrs. Schiavo's family, who favored ongoing tube feeding or with her husband, who stated that it would have been her wish to discontinue it. In either case, you should be able to express your own, personal views on health care. You should have a reasonable assurance that your wishes will be carried out. These matters should never be left to the courts or made public in newspapers.

Mrs. Schiavo did not have a document expressing her instructions about how she wanted to be treated. Her failure to clearly express her desires in writing led to what the Supreme Court once called a "prolonged and anguished vigil" for her family. The Terri Schiavo case brought the courts and the media into what should have been a private matter.

FIVE PROBLEMS WITH SHORT "LIVING WILLS." Many people have fairly short, generic "living wills." Consequently, these documents do not really express their personal wishes. Most of them are little more than forms. There are at least five major problems with the "one size fits all" approach. Many "living wills" would not have helped Mrs. Schiavo because they don't deal with artificial administration of nutrition and water, which some health care providers treat as "comfort care" rather than medical treatment.

First Problem: Many important issues are not addressed. The simple forms, including those in the Connecticut Statutes, just do not deal with some of the most important issues. For example:

Home care and Hospice. Do you want to be taken care of at home instead of a nursing home? If you have a terminal condition, would

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you want hospice care? Would you prefer to receive hospice care at home rather than in a public facility?

Drugs for Pain. If you had a terminal condition and were experiencing intractable pain, what level of medication would you accept? The Connecticut statutory form, and most short documents, merely state: "I do want sufficient pain medication to maintain my physical comfort. I do not intend any direct taking of my life, but only that my dying not be unreasonably prolonged."

If you had a very short life expectancy and extreme pain, would it matter to you if medication might make you drug dependent? Would you want to be pain free even if it meant that you might die sooner? Do you want to remain conscious as along as possible? Most "living wills" do not adequately address these concerns.

Tube feeding and intravenous hydration. If you were permanently unconscious like Mrs. Schiavo, would you want to receive nutrition through a tube and water through an intravenous drip? You should be very specific if, and under what circumstances, it would be acceptable to you to have this medical care withheld or withdrawn.

A doctor's document. We drafted an Advance Directive for a physician who considered hydration as different from nutrition. He did not want non-oral "feeding" but chose to maintain fluids for comfort and also as a way to receive pain medications (but no other medications, such as antibiotics) if needed. He thought that it would make him more comfortable, even if he were in a persistent vegetative state.

Specific unwanted treatment. Are there specific treatments that you are opposed to in all circumstances? For example, in one of the very first Advance Directives we drafted, the client stated that he did not want to receive chemotherapy. We made his intention clear and provided that his Representative consider bringing a suit for damages against anyone who acted contrary to his instructions.

Allergies: why information is vital. Your Representative and all health care providers need to know if you require special treatment or diet. Do you have any allergies, especially to medications and foods? This is truly a case of no knowledge being a dangerous thing. People can be allergic to many substances including drugs, foods or even, as was reported in one Connecticut court case, adhesive tape. Failure to be aware of allergies can have life threatening consequences. **HOW**

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TO DEAL WITH ALLERGIES: We provide information on allergies, in bold type, on the first page of our Advance Directives.

Stopping treatment. Do you see a real difference between not being treated and stopping treatment that has already begun? Some health care providers may insist on continuing treatment in all events because not doing so is "abandoning" the patient.

Anatomical Gifts. Do you want to make anatomical gifts or are you opposed to making them? Do you see a distinction between anatomical gifts for "transplantation and therapy" and those for "medical education and advancement of science"? Designating "donor" on your driver's license or signing a short anatomical gift form could open the door to a medical school anatomy class. Almost all of our clients who make anatomical gifts want them limited to therapeutic use by other people. The choice should be yours.

LITTLE KNOWN FACT: Under Connecticut law, if someone dies in a hospital, the administrator is required to discuss the making of anatomical gifts with members of his or her family. This is a legal obligation. The only way that you can avoid this intrusion into your family's lives at a very difficult time is to express your wishes in an Advance Directive.

Second Problem: No HIPAA authorization – Access to Information Prohibited. A 1996 Federal statute prohibits health care providers from disclosing information about you. You should know for sure that your health care Representative will have the same access to your medical records and physicians that you do, if necessary. The only way to accomplish this is with an Advance Health Care Directive that contains specific "HIPAA language."

Most documents, including the forms in the Connecticut Statutes, do not even mention HIPAA. Under this Federal law, you have to give your Representatives specific written authorization and appoint them as your "personal representatives." Otherwise, doctors cannot share information about you with them. The law provides heavy penalties for providers who give information to unauthorized people.

There is a very strong possibility that you will not receive health care that you want, or that you may be given treatment that you don't want. A properly drafted Advance Health Care Directive should directly reference HIPAA. It should specifically give your Representative the

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right to have access to medical records and discuss treatment options with doctors.

HIPAA STORY: Some years ago, a doctor called one of our clients at home. Because of the restrictions of HIPAA, he couldn't speak with the client's wife. The doctor was finally able to contact the client a few days later. Needless to say, this delay and uncertainty caused some anxiety. All of our Advance Health Care Directives specifically provide that the Representative is authorized to receive information under the HIPAA regulations.

Third Problem: Document not honored. Health care providers sometimes refuse to carry out a Representative's instructions.

A SAD TALE: In one recent Florida case, a jury awarded damages against a nursing home for not heeding the clear directions in an Advance Health Care Directive. Mrs. Neumann, a ninety two year old Alzheimer's patient, had signed a Directive clearly stating that she "did not want to be kept alive by artificial means." As she lay dying in the nursing home, rescue workers arrived and began reviving her. She was rushed to a hospital, where she died six days later after various lifesaving measures, including having a breathing tube inserted in her throat.

Mrs. Neumann probably felt assured that she would be allowed to die with dignity. Instead, her last days were spent receiving invasive, futile and unwanted "treatment." A more detailed, personal, Advance Directive might have avoided Mrs. Neumann's final indignity.

Say what you mean. In an article in a nursing journal, the author noted: "The more specific the Directives, the larger the chance that they will be followed both by the physician and family members."

EXAMPLE: If I develop a terminal condition, and am no longer able to make decisions regarding my medical treatment, my attending physician shall withhold or withdraw life sustaining treatment that is not necessary to my comfort or to alleviate my pain. COMPARE this with the generic "I don't want to be kept alive by artificial means." The emphasis is on quality of life, not on whether a given treatment is "artificial."

Put teeth into it. Of what real use is a document which health care providers can ignore with impunity? Suppose that a physician or facility simply will not act in accordance with your Representative's

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directions? You might want to provide that, in an extreme case, your Representative consider bringing legal action to force recalcitrant providers to comply. A Connecticut Superior Court judge ruled that a physician who acted without communicating with the patient's health care Representative could possibly be liable for negligently causing emotional distress. Might a health care provider be more willing to follow your Representative's instructions if your Advance Directive had language such as this edited provision of our documents:

"Some health care providers may disagree with, or attempt to ignore or circumvent, the directions I have expressed in this Document. I want to discourage non compliance with my directions. In an extreme case, I recommend that my Representative consider instituting an action to recover the costs of medical treatment administered in contravention of my directions, the legal costs of implementing my directions and punitive damages. My Representative should similarly consider instituting an action to recover damages for battery, resulting from the impermissible invasion of my bodily integrity, for breach of my civil rights and for infliction of emotional distress."

Fourth Problem: What if you're not dying – just sick or injured?
"Living wills" deal only with "terminal conditions" or permanent unconsciousness. Suppose that, due to sickness or accident, you were temporarily unable to speak or write. Suppose further that you had a medical condition that was not an emergency, but should be addressed now.

Health care providers might refuse to discuss your condition and treatment plan unless the Probate Court appoints a conservator for you. How would they know what you would want? Would they listen to your family or a close friend? What if there were a disagreement among your family members.

Virtually all "living wills" make no provision for your care if you are sick or injured but are not dying or permanently unconscious. In a real sense, they should not be called "living wills" at all. They are really only "exit visas."

A properly designed Advance Directive provides for your Representative to make health care decisions for you at any time when you are incapacitated and cannot communicate your wishes. It might include language similar to this:

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"When Effective. My Health Care Representatives have the authority to act under this Document and make health care decisions for me at any time or times when I am unable to communicate in any way, even in a rudimentary manner. My Representatives may act under this Document notwithstanding the fact that I am neither in a terminal condition nor permanently unconscious."

Fifth Problem: Expressing your non-medical desires. "Quality of Life" issues may be extremely important to you. Virtually all "living wills" only deal with medical issues. They do not let you express what may be your deepest and most important desires. It is important to let health care providers know what would make you comfortable. Here are two examples of clients' specific requests: