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Topic:

The Economic Impact of Death

Ethical Considerations for Estate Planning

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"Drafting Advance Directives, Ethical Considerations"

ADVANCE DIRECTIVES IN FLORIDA

And

ETHICAL CONSIDERATIONS

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I. FS CHAPTER 765 - FLORIDA HEALTH CARE ADVANCE DIRECTIVES

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II. HISTORY OF HEALTH CARE DIRECTIVES

A. **The Origins of Living Wills.**

1. **1967 - The First Living Will Advocate**: Luis Kutner, Esq., developed the first living will for the " . . . rights of dying people to control decisions about their own medical care." In 1968, Walter F. Sackett, M.D., who was also serving in the Florida legislature, introduced a bill to allow patients to make decisions about use of life-sustaining equipment. The bill failed. It was reintroduced in 1973 and again failed.

2. **1976 - The First Living Will Statute**: Barry Keene presented similar bills in the California legislature in the early 1970's but those were also defeated. In 1976 his bill finally passed and California was the first state to approve Living Wills.

3. **1976 – The First Court Decision**: In 1975, 22-year-old Karen Ann Quinlan overdosed on drugs and was placed on ventilator but remained in a "persistent vegetative state." Father wanted ventilator removed but physicians were concerned about the legality. The courts were petitioned and in 1976 the NJ Supreme Court held that the ventilator could be removed but only because she had previously expressed the wish not to have her life maintained indefinitely: this was the first court decision that validated Advance Directives: *In re Quinlan* (70 N.J. 10, 355 A 2nd 647). Because her reflexes became accustomed to the

assisted breathing from the ventilator during the one year court process, she stabilized after it was removed. However, because her expressed desires only pertained to the ventilator and not the feeding tubes, the tubes were not removed, and she lived another 10 years before she died.

4. **1977 – The States Begin Adoption of LWs**: 43 states had considered Living Wills and seven had enacted legislation approving them. By 1992, all 50 states and the District of Columbia had advance directive legislation.

5. **1983 – The First Health Care Durable Power of Attorney**: California becomes the first state to create a durable power of attorney specifically for health care decisions.

6. **1990 - The Right to Die is Sustained**: Nancy Cruzan was a 33 year old woman who sustained brain damage in a 1983 automobile accident. She never regained consciousness and her life was sustained by feeding tubes for 4 years. The family requested that the tubes be removed after physicians concluded that she would never regain consciousness. The hospital refused. The family petitioned the courts. The State of Missouri objected to the removal because Ms. Cruzan had never told her friends or family that she would not want to be fed through a tube. The family appealed to the U.S. Supreme Court which held that it was a "constitutional right to refuse medical care including feeding tubes." The Court thus recognized an inherent right-to-die and remanded the Cruzan case back to state court in Missouri to determine if there was "***clear and convincing***" evidence that she would have wanted to die (Note this is the same standard used in FS Chapter 765). The family gathered enough evidence from relatives to finally convince the courts that she would have wanted the tubes removed. They were removed December 15, 1990, and she died December 27. *Cruzan v. Director, Missouri Dept. of Health*, 110 SCt 2841, 1990.

   Caveat: See *In Re Michael Martin*, 450 Mich. 204, 538 N.W.2d 399 (1995). Casual statements made by Mr. Martin were insufficient to prove his wishes to be "clear and convincing evidence."

7. **1990 to 2005 – Terri Schiavo Case**: In 1990, Ms. Schiavo, age 26, collapsed at home while being treated for bulimia and suffered severe brain damage. She was then placed on a feeding tube. A malpractice settlement 3 years later resulted in differences between Terri's husband and father, primarily over who should "apply" the funds for her care. In 1998, her husband remarried and had two children. Her parents sued for guardianship but failed. Years later her former husband petitioned the courts to remove the feeding tube, and in 2000, the request was granted. Her parents then sued for an injunction in part based on alleged lack of evidence that Terri would want it removed and in part due to her husband's retention of the malpractice award. Five years, 6 court cases and 33 expert

witnesses later, the remaining funds from the award had been expended for legal fees. Each side was then "funded" by opposing legal organizations and the litigation continued for years until 2003 when the Florida legislature passed "Terri's Law" which allowed the Governor and the Attorney General to intervene only to be struck down by the Florida Supreme Court. In 2005, all courts denied appeals to intervene by the parents, the husband prevailed and the feeding tube was removed. Terri died on March 31, 2005. Case citations are too numerous to list.

8. **1991– U.S. House of Representatives enacted the Patient Self-Determination Act**: which required hospitals receiving Medicaid or Medicare reimbursement to determine if patient have or wish to have Advance Directives.

9. **1992 – Florida Adopts Chapter 765, Health Care Advance Directives**.

10. **2013- All 50 States and District of Columbia have Advance Directive legislation**.

11. **Five Wishes Booklet**: The booklet, "Five Wishes," meets the standards of 40 states' Advance Directive legislation, including Florida. Five Wishes is an Advance Directive checklist and form that can be used as a Living Will and Health Care Surrogate form. See Aging with Dignity URL: www.againwithdignity.org.

Question: Who should prepare Advance Directive forms?

B. **The Cost of Health Care**. In the United States, 25-55 percent of deaths occur in a health care facility. One study reported that in 20 percent of these cases a family member had to quit work. Thirty-one percent (31%) lost all or most of their savings even though 96 percent had insurance. Seventy to ninety percent of people would rather refuse aggressive medical treatment than have their lives medically prolonged.

Question: Should the cost of health care enter affect the decision of a HCS?

C. **Florida Legislative Statement of Intent Regarding Health Care Directives - FS §765.102**:

"(1) The Legislature finds that every competent adult has the fundamental right of self-determination regarding decisions pertaining to his or her own health, including the right to choose or refuse medical treatment. This right is subject to certain interests of society, such as the protection of human life and the preservation of ethical standards in the medical profession.

(2) To ensure that such right is not lost or diminished by virtue of later physical or mental incapacity, the Legislature intends that a procedure be established **to allow a person to plan for incapacity by executing a document or orally designating another person to direct the course of his or her medical treatment upon his or her**

incapacity. Such procedure should be less expensive and less restrictive than guardianship and permit a previously incapacitated person to exercise his or her full right to make health care decisions as soon as the capacity to make such decisions has been regained.

(3) The Legislature recognizes that for some the administration of life-prolonging medical procedures may result in only a precarious and burdensome existence. In order to ensure that the rights and intentions of a person may be respected even after he or she is no longer able to participate actively in decisions concerning himself or herself, and to encourage communication among such patient, his or her family, and his or her physician, the Legislature declares that the laws of this state recognize the right of a competent adult to make an advance directive **instructing his or her physician to provide, withhold, or withdraw life-prolonging procedures, or to designate another to make the treatment decision for him or her in the event that such person should become incapacitated and unable to personally direct his or her medical care**.

(4) The Legislature recognizes the need for all health care professionals to rapidly increase their understanding of end-of-life and palliative care. Therefore, the Legislature encourages the professional regulatory boards to adopt appropriate standards and guidelines regarding end-of-life care and pain management and encourages educational institutions established to train health care professionals and allied health professionals to implement curricula to train such professionals to provide end-of-life care, including pain management and palliative care [**emphasis added**]."

III. DEFINITIONS FS 765.101

A. "**Advance directive**" means a witnessed written document or oral statement in which instructions are given by a principal or in which the principal's desires are expressed concerning any aspect of the principal's health care, and includes, but is not limited to, the designation of a (i) health care surrogate, (ii) a living will, or (iii) an anatomical gift made pursuant to Part V of this chapter. Note that it does not include a Durable Power of Attorney; however, most attorneys use DPOAs in conjunction with an Advance Directive. A DPOA may also incorporate a HCSD.

B. "**End-stage condition**" means an irreversible condition that is caused by injury, disease, or illness which has resulted in progressively severe and permanent deterioration, and which, to a reasonable degree of medical probability, treatment of the condition would be ineffective.

C. "**Incapacity**" **or** "**incompetent**" means the patient is physically or mentally unable to communicate a willful and knowing health care decision. For the purposes of making an anatomical gift, the term also includes a patient who is deceased.

D. "**Life-prolonging procedure**" means any medical procedure, treatment, or intervention, including artificially provided sustenance and hydration, which sustains, restores, or supplants a spontaneous vital function. The term does not include the administration of medication or performance of medical procedure, when such medication or procedure is deemed necessary to provide comfort care or to alleviate pain.

E. "**Living will**" or "declaration" means:

1. A witnessed document in writing, voluntarily executed by the principal in accordance with FS §765.302; or

2. A witnessed *oral* statement made by the principal expressing the principal's instructions concerning life-prolonging procedures.

F. "**Persistent vegetative state**" means a permanent and irreversible condition of unconsciousness in which there is:

1. The absence of voluntary action or cognitive behavior of any kind.

2. An inability to communicate or interact purposefully with the environment.

G. "**Terminal condition**" means a condition caused by injury, disease, or illness from which there is no reasonable medical probability of recovery and which, without treatment, can be expected to cause death.

IV. GENERAL PROVISIONS – PART I

A. **Amendment or revocation of AD**. An AD or a HCSD may be amended or revoked at any time by a competent principal:

1. By means of a signed, dated writing;

2. By means of the physical cancellation or destruction of the advance directive by the principal or by another in the principal's presence and at the principal's direction;

3. By means of an oral expression of intent to amend or revoke; or

4. By means of a subsequently executed advance directive that is materially different from a previously executed advance directive.

B. **Dissolution of Marriage**. The dissolution or annulment of marriage of the principal revokes the designation of the principal's former spouse as a HCS.

C. **Pre-October 1, 1999 Advance Directives**. These are interpreted in accordance with pre-October 1, 1999, laws and not those that are currently in place. These should be updated.

D. **Effective Date of Amendment/Revocation**. Any such amendment or revocation will be effective *when it is communicated* to the surrogate, health care provider, or health care facility. FS §765.104. *Note:* Written communication is not expressly required.

Question: What if a verbal directive is in conflict with a HCSD or LW? What does a non-spouse HCS do if the principal verbally revokes a LW or HCSD?

E. **Recognition of advance directive executed in another state**. An advance directive executed in another state in compliance with the law of that state or of this state is validly executed for the purposes of this chapter. FS §765.112.

F. **Review of HCS or proxy's decision**. The patient's family, the health care facility, or the attending physician, or any other interested person who may reasonably be expected to be directly affected by the HCS or Proxy's decision concerning any health care decision may seek expedited judicial intervention pursuant to rule 5.900 of the Florida Probate Rules, if that person believes:

1. The HCS or Proxy's decision is not in accord with the patient's known desires or the provisions of this chapter;
2. The advance directive is ambiguous, or the patient has changed his or her mind after execution of the advance directive;
3. The HCS or Proxy was improperly designated or appointed, or the designation of the surrogate is no longer effective or has been revoked;
4. The HCS or Proxy has failed to discharge duties, or incapacity or illness renders the surrogate or proxy incapable of discharging duties;
5. The HCS or Proxy has abused powers; or
6. The patient has sufficient capacity to make his or her own health care decisions. FS §765.105.

G. **Limitations on WL Procedures**. Withholding of life-prolonging procedures provided in Chapter do **not** apply to a person who never had capacity to designate a HCS or execute a LW. FS §765.107(2). *Question:* Would this apply to an anencephalic baby?

H. **Health Care Provider's Forms**. A health care provider or health care facility may *not* require a patient to execute an advance directive or to execute a new advance directive using the facility's or provider's forms. The patient's advance directives shall travel with the patient as part of the patient's medical record. A health care provider or health care facility shall be subject to professional discipline and revocation of license

or certification, and a fine of not more than $1,000 per incident, or both, if the health care provider or health care facility, as a condition of treatment or admission, requires an individual to execute or waive an advance directive.

I. **Refusal to Act by Health Care Provider**. A health care provider or facility that refuses to comply with a patient's advance directive, or the treatment decision of his or her surrogate, shall make reasonable efforts to transfer the patient to another health care provider or facility that will comply with the directive or treatment decision. This does not require a health care provider or facility to commit any act which is contrary to the provider's or facility's moral or ethical beliefs, if the patient:

1. Is not in an emergency condition; and
2. Has received written information upon admission informing the patient of the policies of the health care provider or facility regarding such moral or ethical beliefs. FS §765.1105. Note: Be cognizant of policies and rules of religious organizations that own and operate hospitals.

J. **Procedure**. A health care provider or facility that is unwilling to carry out the wishes of the patient or the treatment decision of his or her surrogate because of moral or ethical beliefs must within seven days either:

1. Transfer the patient to another health care provider or facility. The health care provider or facility shall pay the costs for transporting the patient to another health care provider or facility; or
2. If the patient has not been transferred, carry out the wishes of the patient or the patient's surrogate, unless the provisions of FS §765.105 apply (pertaining to review of HCS decisions). FS §765.1105.

K. **Falsification, forgery, or willful concealment**.

1. Any person who willfully conceals, cancels, defaces, obliterates, or damages an advance directive without the principal's consent or who falsifies or forges the revocation or amendment of an advance directive of another, and who thereby causes life-prolonging procedures to be utilized in contravention of the previously expressed intent of the principal, commits a felony of the third degree, punishable as provided in FS §775.082, FS §775.083, or FS §775.084.
2. Any person who falsifies or forges the advance directive of another or who willfully conceals or withholds personal knowledge of the revocation of an advance directive, with the intent to cause a withholding or withdrawal of life-prolonging procedures contrary to the wishes of the principal, and who thereby because of such act directly *causes life-prolonging procedures to be withheld or withdrawn* and death to be hastened, commits a felony of the second degree, punishable as provided in FS §775.082, FS §775.083, or FS §775.084.

L. **Restrictions on providing consent**. Unless the principal expressly delegates such authority to the HCS in writing, or a surrogate or proxy has sought and received court approval pursuant to rule 5.900 of the Florida Probate Rules, a surrogate or proxy may **not** provide consent for:

1. Abortion, sterilization, electroshock therapy, psychosurgery, experimental treatments that have not been approved by a federally approved institutional review board in accordance with 45 C.F.R. part 46 or 21 C.F.R. part 56, or voluntary admission to a mental health facility.

2. Withholding or withdrawing life-prolonging procedures from a pregnant patient prior to viability as defined in FS §390.0111(4).

V. HEALTH CARE SURROGATE - PART II

A. **Definition of Health Care Surrogate (HCS).** A Health Care Surrogate Designation (HCSD) is:

"A **written document** designating a surrogate to make health care decisions for a principal shall be **signed by the principal in the presence of two subscribing adult witnesses**. A principal unable to sign the instrument may, in the presence of witnesses, direct that another person sign the principal's name as required herein. An exact copy of the instrument shall be provided to the surrogate [emphasis added]." FS §765.202. See FS §765.203 for HCSD form.

B. **HCS cannot be a witness**. The HCS may not be a witness to the HCSD. At least one person who acts as a witness shall be neither the principal's spouse nor blood relative.

C. **Alternate HCS**. A document designating a health care surrogate (HCS) may also designate an *alternate surrogate* provided the designation is explicit. The alternate HCS may assume his or her duties as surrogate for the principal if the original HCS is unwilling or unable to perform his or her duties. The principal's failure to designate an alternate HCS shall not invalidate the designation.

Question: May there be Co-HCSs?

D. **Separate Mental Health HCS**. A separate HCS may be designated to consent to mental health treatment if (i) the principal is determined by a court to be incompetent to consent to mental health treatment and (ii) a guardian advocate is appointed as provided under FS §394.4598. However, unless the document designating the health care surrogate expressly states otherwise, the court shall assume that the health care

surrogate authorized to make health care decisions under this chapter is also the principal's choice to make decisions regarding mental health treatment.

E. **Duration.** Unless the HCSD states a time of termination, the designation shall remain in effect until revoked by the principal. See FS §765.104 for revocation and amendment, discussed *infra*.

F. **Presumption of validity**. A written designation of a HCSD establishes a rebuttable presumption of clear and convincing evidence of the principal's designation of the surrogate. A principal is presumed to be capable of making health care decisions for herself or himself unless she or he is determined to be incapacitated. Incapacity may not be inferred from the person's voluntary or involuntary hospitalization for mental illness or from her or his mental retardation.

G. **Determination of Capacity to make HCSD**.

1. **Evaluation by Physician**. If a principal's capacity to make health care decisions for herself or himself or provide informed consent is in question, the attending physician shall evaluate the principal's capacity. If the physician concludes that the principal lacks capacity that determination is entered in the principal's medical record. If the attending physician has a question as to whether the principal lacks capacity, another physician shall also evaluate the principal's capacity, and if the second physician agrees that the principal lacks the capacity to make health care decisions or provide informed consent, the health care facility shall enter both physicians' evaluations in the principal's medical record.

2. **Notification of HCS**. If the principal has designated a HCS or has delegated authority to make health care decisions to an attorney-in-fact under a durable power of attorney, the facility shall notify such HCS or attorney in fact in writing that her or his authority under the instrument has commenced, as provided in Chapter 709 or FS §765.203.

3. **Commencement of HCS Authority**. The authority of the HCS commences upon a determination that the principal lacks capacity.

4. **No other use**. A determination made pursuant to this section that a principal lacks capacity to make health care decisions shall not be construed as a finding that a principal lacks capacity for any other purpose. *Note*: it likely may be introduced as evidence if testamentary capacity is an issue.

5. **Counseling clients with diminished capacities**: The Florida Bar and The Rules of Professional Conduct, Rule 4-1.14:

> "(a) The fact that a client suffers a disability does not diminish the lawyer's obligation to treat the client with attention and respect. If the person has no guardian or legal representative, the lawyer often must act as de facto

guardian. Even if the person does have a legal representative, the lawyer should as far as possible accord the represented person the status of client, particularly in maintaining communication.

Comment 2. The fact that a client suffers a disability does not diminish the lawyer's obligation to treat the client with attention and respect. If the person has no guardian or legal representative, the lawyer often must act as de facto guardian. Even if the person does have a legal representative, the lawyer should as far as possible accord the represented person the status of client, particularly in maintaining communication."

The attorney's obligation to the client may put the attorney between the client and the client's family relative to Advance Directives.

H. **Notification if HCS is a nonspouse**. Upon commencement of the HCS's authority, a HCS who is not the principal's spouse shall notify the principal's spouse or adult children of the principal's designation of the HCS. If the attending physician determines that the principal has regained capacity, the authority of the HCS shall cease, but shall recommence if the principal subsequently loses capacity. *Note:* It is likely notice is frequently not given to spouse by nonspouse HCS.

I. **HCS Implementation with Living Will**. If the HCS is required to consent to withholding or withdrawing life-prolonging procedures, the provisions of Part III shall apply, i.e., Living Will statutes control.

J. **Responsibility of the HCS**. Unless such authority has been expressly limited by the principal, the HCS shall:

1. Have authority to act for the principal and to make all health care decisions for the principal during the principal's incapacity.

2. Provide written consent using an appropriate form whenever consent is required, including a physician's order not to resuscitate (discussed infra).

3. Consult expeditiously with appropriate health care providers to provide informed consent, and make only health care decisions for the principal which he or she believes the principal would have made under the circumstances if the principal were capable of making such decisions.

4. Be provided access to the appropriate medical records of the principal.

Question: *Doesn't HIPAA require a separate form for medical record disclosure? See Attachment A.*

Question: Is there a finite duration for a HIPAA disclosure form? See Attachment A.

5. Apply for public benefits, such as Medicare and Medicaid, for the principal and have access to information regarding the principal's income and assets and banking and financial records to the extent required to make application. FS §765.205.

K. **Appointment of Guardian by Court**.

1. HCS authority continues unless Court Order appointing the guardian states otherwise. If, after the appointment of a HCS, a court appoints a guardian, the HCS shall continue to make health care decisions for the principal, unless the court has modified or revoked the authority of the HCS pursuant to FS §744.3115. The HCS may be directed by the court to report the principal's health care status to the guardian.

2. Court must determine if HCSD exists. In each proceeding in which a guardian is appointed, the court shall determine whether the ward, prior to incapacity, has executed any valid advance directive under Chapter 765. If any advance directive exists, the court shall specify in its order and letters of guardianship what authority, if any, the guardian shall exercise over the surrogate. Pursuant to the grounds listed in FS §765.105, the court, upon its own motion with notice to the surrogate and any other appropriate parties, may modify or revoke the authority of the HCS to make health care decisions for the ward. FS §744.3115.

VI. LIFE-PROLONGING PROCEDURES (Living Wills) - PART III

A. **Definition of Living Will (LW)**. Any competent adult may, at any time, make a LW or written declaration and direct the providing, withholding, or withdrawal of life-prolonging procedures in the event that such person has a (i) *terminal condition*, (ii) has an *end-stage condition*, or (iii) is in a *persistent vegetative state*. See FS 765.303 for LW form.

B. **Witnesses**. A LW must be signed by the principal in the presence of two subscribing witnesses, one of whom is neither a spouse nor a blood relative of the principal. If the principal is physically unable to sign the LW, one of the witnesses must subscribe the principal's signature in the principal's presence and at the principal's direction. Note: possible conflict with FS 765.101(11) for oral LW.

C. **Notification to physician by principal**. It is the responsibility of the principal to provide for notification to her or his attending or treating physician that the LW has

been made. If the principal is physically or mentally incapacitated at the time the principal is admitted to a health care facility, any other person may notify the physician or health care facility of the existence of the LW. An attending or treating physician or health care facility which is so notified shall promptly make the LW or a copy thereof a part of the principal's medical records. FS §765.302(1).

D. **Rebuttable Presumption of validity**. A LW establishes a *rebuttable presumption* of clear and convincing evidence of the principal's wishes.

E. **Possible Conflict Scenarios: HCSD v. LW**.

1. ***HCSD exists but silent governing life-prolonging procedures - LW exists***. If a person has made a LW expressing his or her desires concerning life-prolonging procedures, and has designated a HCS for health care decisions but *not* for life-prolonging procedures, the attending physician *may* proceed as directed by the principal in the LW but is not mandated to proceed with removal. If dispute, the procedures in FS §765.105 control.

   Note: it is important to consider whether the HCSD should empower the HCS to make LW decisions. Also consider language that *mandates* no life-prolonging procedures be used, assuming that is enforceable. Is it?

2. ***HCSD exists but silent governing life-prolonging procedures- no LW***. In the absence of a LW, the decision to withhold or withdraw life-prolonging procedures from a patient may be made by a HCS designated by the patient unless the HCSD limits the surrogate's authority to consent to the withholding or withdrawal of life-prolonging procedures. FS §765.305.

   Default: the HCSD gives LW decision authority to HCS absent an express limitation in the HCSD itself but even if there is LW the attending physician *may* disregard if HCSD objects.

F. **Procedure to implement withholding of life-prolonging procedures**. Before proceeding in accordance with the principal's LW or HCSD, it must first be determined that:

1. The principal does not have a reasonable medical probability of recovering capacity so that the right could be exercised directly by the principal.
2. The principal has a terminal condition, has an end-stage condition, or is in a persistent vegetative state.
3. Any limitations or conditions expressed orally or in a written declaration have been carefully considered and satisfied. FS §765.305

Question: Should or can the LW direct that estate tax and/or cost of healthcare be considered in withholding life-prolonging procedures: Or *extending* them? Does this create a potential ethical conflict when HCSD is selected?

G. **Determination of patient condition by two physicians**. In determining whether the patient has a (i) terminal condition, (ii) has an end-stage condition, (iii) is in a persistent vegetative state, (iv) may recover capacity, or (v) whether a medical condition or limitation referred to in an advance directive exists, the patient's attending or treating physician and at least one other consulting physician must separately examine the patient. The findings of each such examination must be documented in the patient's medical record and signed by each examining physician before life-prolonging procedures may be withheld or withdrawn. FS §765.306.

H. **Disputes**. In the event of a dispute or disagreement concerning the attending physician's decision to withhold or withdraw life-prolonging procedures, the attending physician shall not withhold or withdraw life-prolonging procedures pending review under FS §765.105. If a review of a disputed decision is not sought within seven days following the attending physician's decision to withhold or withdraw life-prolonging procedures, the attending physician may proceed in accordance with the principal's instructions. FS §765.304(2).

I. **How effective are LWs in actuality – have they failed**?

1. One study showed that in 30 of 39 cases, the HCS designated in the HCSD were not the ones who made health care decisions.
2. " . . . LWs seem not to affect patients' treatments."
3. "We should repeal the PSDA, which was passed with an arrogant indifference to its effectiveness and its cost and which today imposes accumulating paperwork and administrative expense for paltry rewards."
4. "Researchers found that 90 percent of respondents determined after review of the living will that the patient's code status was DNR and 92 percent defined their understanding of DNR as comfort care/end of life care."
5. A health care provider or hospital generally need not comply with a LW in Florida. See FS §765.1105(1)

J. **Location of LWs**. Where do patients keep LWs? Safe deposit box? Attorney's office? How can they be used if not readily available? Gunster uses laminated cards that advise existence of LW, DPOA, HIPAA and HCSD, where they are and who to contact. Note that Advance Directives are not necessarily shared among health care providers and generally must be given to each one separately.

VII. ABSENCE OF ADVANCE DIRECTIVE - PART IV

A. **No HCS and no LW**. If an incapacitated or developmentally disabled patient has not executed an advance directive, or designated a HCS to execute an advance directive, or the designated or alternate HCS is no longer available to make health care decisions, health care decisions may be made for the patient by any of the following individuals ("proxy"), in the following order of priority, if no individual in a prior class is reasonably available, willing, or competent to act:

1. The **judicially appointed guardian** of the patient or the guardian advocate of the person having a developmental disability as defined in FS §393.063, who has been authorized to consent to medical treatment, if such guardian has previously been appointed; however, this paragraph shall not be construed to require such appointment before a treatment decision can be made under this subsection;
2. The patient's spouse;
3. An adult child of the patient, or if the patient has more than one adult child, a majority of the adult children who are reasonably available for consultation;
4. A parent of the patient;
5. The adult sibling of the patient or, if the patient has more than one sibling, a majority of the adult siblings who are reasonably available for consultation;
6. An adult relative of the patient who has exhibited special care and concern for the patient and who has maintained regular contact with the patient and who is familiar with the patient's activities, health, and religious or moral beliefs; or
7. A **close friend** of the patient.
8. A clinical social worker licensed pursuant to chapter 491, or who is a graduate of a court-approved guardianship program. FS §765.401(1).

B. **Patient's best interests**. Any health care decision made under this part must be based on the proxy's informed consent and on the decision the proxy reasonably believes the patient would have made under the circumstances. If there is no indication of what the patient would have chosen, the proxy may consider the patient's best interest in deciding that proposed treatments are to be withheld or that treatments currently in effect are to be withdrawn.

C. **Procedure**. Before exercising the incapacitated patient's rights to select or decline health care, the proxy must comply with the provisions of FS §765.205 (responsibility of the HCS) and FS §765.305 (procedures of HCS in absence of LW), *except that a proxy's decision to withhold or withdraw life-prolonging procedures (i) must be*

supported by clear and convincing evidence that the decision would have been the one the patient would have chosen had the patient been competent ***or****,(ii) if there is no indication of what the patient would have chosen, that the decision is in the patient's best interest.* FS §765.401(2). Presumably, FS §765.306 (requiring two physicians' determinations) are also required. *Note:* A HCSD or LW is required if the principal wishes to be certain that life-prolonging procedures are not to be withdrawn.

D. **Special Rules for Persistent Vegetative State (PVS)**.

1. PVS is determined by the attending physician in accordance with currently accepted medical standards.

2. Persons without a LW or HCSD for whom there is no evidence indicating what the person would have wanted under such conditions, and for whom, after a reasonably diligent inquiry, no family or friends are available or willing to serve as a proxy to make health care decisions for them, life-prolonging procedures may be withheld or withdrawn under the following conditions:

   a) The person has a *judicially appointed guardian* representing his or her best interest with authority to consent to medical treatment; *and*

   b) The guardian and the person's attending physician, in consultation with the medical ethics committee of the facility where the patient is located, conclude that the condition is permanent and that there is no reasonable medical probability for recovery and that the withholding or withdrawing life-prolonging procedures is in the best interest of the patient. FS §765.404. *Note*: this requirement relating to PVS appears only to apply where there is no AD in existence.

   c) Case examples:

      (1) Terri Schiavo. She had no Advance Directive although FS §765.401, Proxy, was enacted in 1992. Husband wanted to remove from feeding tube but parents objected. Husband ultimately prevailed and feeding tube was removed.

      (2) Zarko Sekerez. In 2011, Sekerez was admitted to hospital. He had a terminal form of leukemia but complained of dehydration and shingles. He was diagnosed with bacterial pneumonia and was given a blood thinner. After his first dose he refused subsequent treatment, and it was so noted in his chart. Subsequent doses were administered, and he later died. His family sued the hospital. Defendants argued "medical emergency" although hospital policy required consent for treatment. Case settled in 2012.

      (3) Madeline Neumann. The 92 year old was found unresponsive in nursing home bed but still breathing. She had a LW and a DNR.

Paramedics were called and revived her. The family sued the nursing home and physician medical director. Nursing home was found liable but not the physician.

E. **No euthanasia**. "Nothing in this chapter shall be construed to condone, authorize, or approve mercy killing or euthanasia, or to permit any affirmative or deliberate act or omission to end life other than to permit the natural process of dying."

VIII. DO NOT RESUSCITATE ORDER

A. **DNR Order**. This is a yellow, pre-hospital DNR Order Form – DH Form 1896 issued by the Florida Department of Health. Florida Regulations 64B8-9.016. *It is valid only in Florida*. See Attachment B.

B. **DNR Order Effect**. A DNR Order means "do not employ any resuscitative efforts in the event of the patient's cardiac or respiratory arrest." It does not mean "do not treat." All other prescribed treatments such as pain medications, fluids, antibiotics, etc., continue as ordered unless LW specifies otherwise.

Relevant statistics:

1. In May, 2012, The Journal of Emergency Medicine found that 78 percent of physicians misinterpreted LWs as DNRs.
2. QuantiaMD is an online physician learning collaborative that found that:
   (1) nearly 50 percent of 10,000 health care professionals who were surveyed misunderstood the components of LWs.
   (2) Twenty percent (20%) said that they would defibrillate a patient without a pulse who had a clear DNR Order.
3. One 2012 study found that 78% of physicians (including ER physicians) misinterpreted LWs as DNR Orders.

C. **Three Conditions for Pre-hospital DNR**. It must: (1) be on yellow paper; (2) be signed by patient and patient's doctor; and, (3) the patient *must* have or is in the three end-stage conditions and determination must be made by physician before the order is written. However, if a patient is admitted into the hospital for an acute illness and not in an end-state condition, the patient may instruct physician to refuse treatment.

D. **Minors**. A parent has authority to consent to a DNR Order for a minor.

E. **Revocation**. The DNR Order may be revoked by the patient if patient has capacity. If patient does not have capacity, LW may direct or HCS, if any. If patient does not

have LW or HCS, same order of priority for selection of Proxy is used. The DNR Order may be rescinded by attending physician by telephone.

F. **Effect of LW on DNR**. A LW may reflect desire that upon cardiac or respiratory arrest, life-prolonging procedures not be given but the patient's medical chart must still reflect a determination that one of the three end-state conditions before a DNR Order is written.

G. **Third Party Objection to DNR**. What happens if the patient's family objects to the DNR Order if the intention is reflected in the LW and patient is incapacitated? Note a HCS may not enter a DNR for an incapacitated patient who is two months pregnant and in an end-stage condition unless the authority is expressly delegated to the HSC by the patient while having capacity.

Question: Can a DNR Order be unilaterally issued by a hospital or health care provider and against the patient's and his/her family's wishes? - **yes**, at least in Canada.

IX. ANATOMICAL GIFTS
Part V (Uniform Anatomical Gift Act)

A. **Statement of Legislative Intent**:

"Because of the rapid medical progress in the fields of tissue and organ preservation, transplantation of tissue, and tissue culture, and because it is in the public interest to aid the medical developments in these fields, the Legislature in enacting this part intends to encourage and aid the development of reconstructive medicine and surgery and the development of medical research by facilitating premortem and postmortem authorizations for donations of tissue and organs. It is the purpose of this part to regulate the gift of a body or parts of a body, the gift to be made after the death of a donor." FS §765.510.

B. **Definitions**.

1. "**Anatomical gift (AG)**" or "gift" means a donation of all or part of a human body to take effect after the donor's death and to be used for transplantation, therapy, research, or education.

2. "**Death**" means the absence of life as determined, in accordance with currently accepted medical standards, by the irreversible cessation of all respiration and circulatory function, or as determined, in accordance with FS §382.009, by the irreversible cessation of the functions of the entire brain, including the brain stem.

C. **Who may make an AG**. Any person who may make a Will may make an AG of his or her body.

D. **Presumption of validity absent revocation**. If the decedent makes an AG by one of the methods listed in FS §765.514(1) (discussed *infra*.), then in the absence of actual notice of contrary indications by the decedent, the document or entry in the donor registry is legally sufficient evidence of the decedent's informed consent to donate an AG.

E. **Irrevocable after death**. An AG made by a qualified donor that has not been revoked by the donor as provided in FS §765.516 is *irrevocable after the donor's death*. A family member, guardian, representative ad litem, or health care surrogate may not modify, deny, or prevent a donor's wish or intent to make an AG after the donor's death.

F. **HCS may make AG of principal**. A health care surrogate designated by the decedent pursuant to Part II of this chapter may give all or any part of the decedent's body for any purpose specified in FS §765.513 **absent actual notice of contrary indications by the decedent**. FS §765.712(2)

Question: Shouldn't client be made aware of this default permission to HCS? See also FS §765.516 for termination or revocation procedure by donor: HCS not apparently authorized to amend or revoke.

G. **Procedure if no AG gift document found or no HCSD**. A member of one of the classes of persons listed below, in the order of priority listed and in the absence of actual notice of contrary indications by the decedent or actual notice of opposition by a member of a prior class, may give all or any part of the decedent's body for any purpose specified in FS §765.513:

1. The **spouse** of the decedent;
2. An **adult child** of the decedent;
3. Either **parent** of the decedent;
4. An **adult sibling** of the decedent;
5. An **adult grandchild** of the decedent;
6. A **grandparent o**f the decedent;
7. A **close personal friend**, as defined in FS §765.101;
8. A **guardian of the person** of the decedent at the time of his or her death; or
9. A **representative ad litem** appointed by a court of competent jurisdiction upon a petition heard ex parte filed by any person. FS §765.512.

The AG may be made immediately after death or *before* death. FS 765.512(5). Q*uestion:* can a pre-death AG be made that could result in death?

H. **Donees and purposes for AGs**. Permissible donees and purposes are:

1. Any procurement organization or accredited medical or dental school, college, or university for education, research, therapy, or transplantation or a nontransplant anatomical donation organization defined in FS §406.49.
2. Any individual specified by name for therapy or transplantation needed by him or her. FS §765.513.

I. **Manner of making AG**:

1. Tissue donor card.
2. Registering online with the donor registry.
3. Signifying intent to donate on his or her driver's license or identification card issued by the DMV. Revocation, suspension, expiration, or cancellation of the driver's license or identification card does not invalidate the gift.
4. Expressing a wish to donate in a LW or other advance directive.

5. Executing a will that includes a provision indicating that the testator wishes to make an AG. The gift becomes effective upon the death of the testator without waiting for probate. If the Will is not probated or if it is declared invalid for testamentary purposes, the gift is nevertheless valid to the extent that it has been acted upon in good faith.

6. Expressing a wish to donate in a document other than a Will. The document must be signed by the donor in the presence of two witnesses who shall sign the document in the donor's presence. FS §765.514. Uniform Donor Card form is in FS §765.514(f).

J. **Delivery of donor gift document**. If an AG is made pursuant to FS §765.521, the completed donor registration card shall be delivered to the department, and the department must communicate the donor's intent to the donor registry, but delivery is not necessary to the validity of the gift. If the donor withdraws the gift, the records of the department must be updated to reflect such withdrawal, and the department must communicate the withdrawal to the donor registry for the purpose of updating the registry.

K. **Specified Donee**. If an AG is made by the donor to a specified donee, the document of gift, other than a Will, may be delivered to the donee to expedite the appropriate procedures immediately after death, but delivery is not necessary to the validity of the gift. The document of gift may be deposited in any hospital, bank, storage facility, or registry office that accepts such documents for safekeeping or to facilitate the donation of organs and tissue after death.

L. **Donor registry and education program**. The Agency for Health Care Administration (ACHA) and the Department of Highway Safety and Motor Vehicles (DMV) jointly contracts for the operation of a donor registry and education program.

M. **AG information is confidential**. Information held in the donor registry which identifies a donor is confidential and exempt from FS §119.07(1) and FS §24(a), Art. I of the State Constitution. FS §765.51551.

N. **Donor amendment or revocation of AG.** A donor may amend the terms of or revoke an AG by:

1. The execution and delivery to the donee of a signed statement witnessed by at least two adults, at least one of whom is a disinterested witness.

2. An oral statement that is made in the presence of two persons, one of whom is not a family member, and communicated to the donor's family or attorney or to the donee. An oral statement is effective only if the procurement organization,

transplant hospital, or physician or technician has actual notice of the oral amendment or revocation before an incision is made to the decedent's body or an invasive procedure to prepare the recipient has begun.

3. A statement made during a terminal illness or injury addressed to an attending physician, who must communicate the revocation of the gift to the procurement organization.

4. A signed document found on or about the donor's person.

5. Removing his or her name from the donor registry.

6. A later-executed document of gift which amends or revokes a previous AG or portion of an AG, either expressly or by inconsistency.

7. By the destruction or cancellation of the document of gift or the destruction or cancellation of that portion of the document of gift used to make the gift with the intent to revoke the gift.

8. Any AG made by a will may also be amended or revoked in the manner provided for the amendment or revocation of Wills or as provided in paragraph (1)(a) of FS §765.516.

Note: While a HCS may consent to an AG absent a contrary statement in the HCSD, it does not appear that a HCS may amend or revoke. FS §765-516.

O. **<u>Donations as part of driver license or identification card process</u>**.

ACHA DMV has implemented a program encouraging and allowing persons to make AGs as a part of the process of issuing identification cards and issuing and renewing driver licenses. The donor registration card distributed by DMV includes the information required by the uniform donor card under FS §765.514 and such additional information as determined necessary by the DMV. The DMV also has a program to identify donors which includes notations on identification cards, driver licenses, and driver records or such other methods to clearly indicate the individual's intent to make an AG. A notation on an individual's driver license or identification card that the individual intends to make an AG satisfies all requirements for consent to organ or tissue donation.

ATTACHMENT A

HIPAA COMPLIANCE CHECKLIST

See http://www.hhs.gov/hipaafaq/use/

HIPAA does not technically require a written document for disclosure but virtually all health care providers use them for their own protection. No specific format is required but the following are some of the factors to be considered in drafting a disclosure/release form

- What health information will be disclosed
- Who will disclose the information
- Who will receive the information. This can be done by categories, e.g., any physician, any hospital, etc.
- The purpose(s) for disclosing the information
- A statement informing the patient of: (1) his/her right to revoke the authorization in writing; (2) how to revoke the authorization; and, (3) any exceptions to the right to revoke
- A statement that the health care provider cannot require the patient to sign the authorization in order to receive treatment or payment or to enroll or be eligible for benefits
- A statement that information disclosed pursuant to the authorization may be redisclosed by the recipient and no longer protected by the federal privacy regulations
- ***A statement that the authorization will expire***: (1) on a specific date; (2) after a specific amount of time, e.g., 5 years; or, (3) upon the occurrence of some event related to the patient [***emphasis added***].
- The signature of the patient and the date. If a health care surrogate or attorney in fact signs the authorization, the authorization must include a description of that person's authority to act for the patient. No witness or notarization is required.

ATTACHMENT B

DO NOT RESUSCITATE ORDER

ATTACHMENT C

THE FLORIDA BAR

RULES OF PROFESSIONAL CONDUCT

RULE 4-1.14 CLIENT UNDER A DISABILITY

(a) Maintenance of Normal Relationship. When a client's ability to make adequately considered decisions in connection with the representation is impaired, whether because of minority, mental disability, or for some other reason, the lawyer shall, as far as reasonably possible, maintain a normal client-lawyer relationship with the client.

(b) Appointment of Guardian. A lawyer may seek the appointment of a guardian or take other protective action with respect to a client only when the lawyer reasonably believes that the client cannot adequately act in the client's own interest.

Comment

The normal client-lawyer relationship is based on the assumption that the client, when properly advised and assisted, is capable of making decisions about important matters. When the client is a minor or suffers from a mental disorder or disability, however, maintaining the ordinary client-lawyer relationship may not be possible in all respects. In particular, an incapacitated person may have no power to make legally binding decisions. Nevertheless, a client lacking legal competence often has the ability to understand, deliberate upon, and reach conclusions about matters affecting the client's own well-being. Furthermore, to an increasing extent the law recognizes intermediate degrees of competence. For example, children as young as 5 or 6 years of age, and certainly those of 10 or 12, are regarded as having opinions that are entitled to weight in legal proceedings concerning their custody. So also, it is recognized that some persons of advanced age can be quite capable of handling routine financial matters while needing special legal protection concerning major transactions.

The fact that a client suffers a disability does not diminish the lawyer's obligation to treat the client with attention and respect. If the person has no guardian or legal representative, the lawyer often must act as de facto guardian. Even if the person does have a legal representative, the lawyer should as far as possible accord the represented person the status of client, particularly in maintaining communication.

If a legal representative has already been appointed for the client, the lawyer should ordinarily look to the representative for decisions on behalf of the client. If a legal representative has not been appointed, the lawyer should see to such an appointment where it would serve the client's best interests. Thus, if a disabled client has substantial property that should be sold for the client's benefit, effective completion of the transaction ordinarily requires appointment of a legal representative. In many circumstances, however, appointment of a legal representative may be

expensive or traumatic for the client. Evaluation of these considerations is a matter of professional judgment on the lawyer's part.

If the lawyer represents the guardian as distinct from the ward and is aware that the guardian is acting adversely to the ward's interest, the lawyer may have an obligation to prevent or rectify the guardian's misconduct. See rule 4-1.2(d).

Disclosure of client's condition
Rules of procedure in litigation generally provide that minors or persons suffering mental disability shall be represented by a guardian or next friend if they do not have a general guardian. However, disclosure of the client's disability can adversely affect the client's interests. The lawyer may seek guidance from an appropriate diagnostician.

Amended July 23, 1992, effective Jan. 1, 1993 (605 So.2d 252).

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3 RULES OF DISCIPLINE
3-4 STANDARDS OF CONDUCT

RULE 3-4.2 RULES OF PROFESSIONAL CONDUCT

Violation of the Rules of Professional Conduct as adopted by the rules governing The Florida Bar is a cause for discipline.

[Revised: 10-22-2009]