HOUSE OF REPRESENTATIVES STAFF ANALYSIS

BILL #: HB 701 CS Withholding or Withdrawal of Nutrition or Hydration from

Incompetent Persons

SPONSOR(S): Baxley and others

TIED BILLS: SB 2128 IDEN./SIM. BILLS: Similar

REFERENCE	ACTION	ANALYST	STAFF DIRECTOR
1) Health Care Regulation Committee	7 Y, 4 N, w/CS	Hamrick	Mitchell
2) Judiciary Committee			
3) Health & Families Council			
4)			
5)			

SUMMARY ANALYSIS

CS REVSION

The CS for HB 701 creates the Starvation and Dehydration of Incompetent Persons Prevention Act (Part VI of Ch. 765) to establish for some cases a presumption that an incompetent person has directed their health care providers to supply him or her with the nutrition and hydration necessary to sustain life. The presumption would NOT apply to a person who has executed a written advance directive or living will. Nor would the presumption apply when there is clear and convincing evidence that the person expressly authorized withdrawing or withholding nutrition or hydration in applicable circumstances.

In addition to the above situations where the patient has provided direction, the CS for HB 701 provides that the presumption does not apply under the following situations when providing nutrition or hydration:

- Is not medically possible;
- Would hasten death:
- Would cause severe, intractable or significant long-lasting pain;
- Would cause significant medical harm;
- Would not contribute to sustaining life;
- Would not provide comfort to the incompetent person;
- Or when death resulting from a terminal illness or injury is imminent and the purpose of acting is not to cause death by starvation or dehydration;

The right to refuse or consent to medical treatment and the rights or responsibilities of health care providers, competent or incompetent persons, minors, and a patient's family are preserved in s. 765.106, F.S. The Starvation and Dehydration of Incompetent Persons Prevention Act limits the effect of s. 765.106, F.S., to the extent that the act narrows the right to have nutrition and hydration withheld to those specified in the bill.

The bill provides that the Starvation and Dehydration of Incompetent Persons Prevention Act applies to all persons living, and to all health care decisions not executed prior to the effective date.

The bill provides legislative intent and a minimum time period that a guardian or proxy must be present with a ward or patient. The bill also places limits on the authority to have nutrition or hydration withheld or withdrawn.

The CS for HB 701 provides that this act shall take effect upon becoming law.

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FULL ANALYSIS

I. SUBSTANTIVE ANALYSIS

A. HOUSE PRINCIPLES ANALYSIS:

Provide limited government - The bill places limitations on end-of-life decisions.

Safeguard individual liberty – The bill preserves life while eliminating substituted judgment in cases where incompetent persons have not expressly authorized a refusal of nutrition and hydration.

Promote personal responsibility – The bill encourages individuals to complete advance directives and living wills that specify their wishes concerning the withholding or withdrawing of nutrition and hydration.

Empower families – The bill reduces the instances where families will have responsibility or authority to refuse nutrition or hydration on behalf of their loved ones.

B. EFFECT OF PROPOSED CHANGES:

The Committee Substitute for HB 701 creates the Starvation and Dehydration of Incompetent Persons Prevention Act (Part VI of Ch. 765, F.S.) to establish a presumption that an incompetent person has directed their health care providers to supply him or her with the nutrition and hydration necessary to sustain life.

Where applicable, the presumption would prohibit the intentional starvation or dehydration of incompetent persons. The presumption would NOT apply to a person who has executed a written advance directive or living will. Nor would the presumption apply when there is clear and convincing evidence that the person expressly authorized withdrawing or withholding nutrition or hydration in applicable circumstances. (This oral authorization would constitute an advance directive under s. 765.101(1), F.S.).

In addition to the above situations where the patient has provided direction, the CS for HB 701 provides that the presumption does not apply when, in reasonable medical judgment, providing nutrition or hydration:

- Is not medically possible;
- Would hasten death;
- Would cause severe, intractable or significant long-lasting pain;
- Would cause significant medical harm;
- Would not contribute to sustaining life;
- Would not provide comfort to the incompetent person;
- Or when death resulting from a terminal illness or injury is imminent and the purpose of acting is not to cause death by starvation or dehydration;

The circumstances included in the last point would have to be confirmed by a second physician in addition to the incompetent person's treating physician.

The right to refuse or consent to medical treatment and the rights or responsibilities of health care providers, competent or incompetent persons, minors, and patient's family are preserved in s. 765.106, F.S. The Starvation and Dehydration of Incompetent Persons Prevention Act limits the effect of s. 765.106, F.S., to the extent that the act narrows the right to have nutrition and hydration withheld to those specified in the bill.

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The bill also provides that the Starvation and Dehydration of Incompetent Persons Prevention Act does not repeal the Florida Medical Consent law (s. 766.103, F.S.), and that the Florida Medical Consent Law cannot be used to violate the Act. The bill provides that the Medical Consent Law may be used as an alternative to the Starvation and Dehydration of Incompetent Persons Prevention Act.

The bill provides definitions for "nutrition," and "reasonable medical judgment." The bill adds the presumption that a "developmentally disabled" principal, who is a competent adult executing an advance directive and on whose behalf health care decisions are to be made, is capable of making health care decisions until they are determined incapacitated.

HB 701 CS also provides that the bioethics committee that reviews a decision to withhold or withdraw life-prolonging procedures must be the same committee involved in the selection of a proxy.

The bill provides that the Starvation and Dehydration of Incompetent Persons Prevention Act applies to and protects all living persons. The bill also provided that its provisions are remedial and intended to regulate health care decisions made prior to the effective date of the Act but not executed before then.

The Committee Substitute adds language restricting the authority of a guardian or proxy who has engaged in conduct prohibited for guardians under s. 744.446, F.S. The bill also directs that the statutory decision-maker may not avoid the responsibility to make health care decisions by petitioning a court to make such decisions. The bill prohibits judges from making any decision to withhold or withdraw nutrition or hydration from a person in a persistent vegetative state. Instead, judges are expected to serve as unbiased judges of petitions questioning such decisions once made.

The Committee Substitute also amends s. 765.401 by adding a provision that a proxy may not withhold nutrition and hydration from an incompetent patient unless the proxy has spent a specified amount of time present with the incompetent person during the three months previous to a decision or to the execution of the decision.

The bill declares that the statutory law of the state provides the exclusive legal basis for end-of-life health care decisions in Florida and chapter 765 constitutes and occupies the entire body of law regulating such decisions.

The bill, both expressly, and in its general intent, establishes that public policy prohibits starvation or dehydration by withholding nutrition and hydration except in the circumstances specifically authorized.

HB 701 CS provides that this act shall take effect upon becoming law.

CURRENT SITUATION

Right to Make Decisions about Health Care

Federal and state statutory and case laws provide that each legally competent adult person has the right to make decisions about the amount, duration, and type of medical treatment they wish to receive, including the right to refuse or to discontinue medical treatment.¹ The State Supreme Court has recognized four state interests which might, on a case by case basis, override this constitutional right with respect to health care decisions which would result in the person's death: preservation of life; the protection of innocent third parties; the prevention of suicide; and maintenance of the ethical integrity of the medical profession.

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¹ Satz v. Perlmutter, 379 So.2d 359 (Fla. 1980)(the right of a competent, but terminally ill person, to refuse medical treatment); John F. Kennedy Memorial Hospital, Inc. v. Bludworth, 452 So.2d 921 (Fla. 1984)(the right of an incapacitated ("incompetent") terminally ill person to refuse medical treatment); Wons v. Public Health Trust of Dade County, 541 So.2d 96 (Fla. 1989)(the right of a competent but not terminally ill person to refuse medical treatment); In re Guardianship of Browning, 568 So.2d 4 (Fla. 1990)(the right of an incapacitated but not terminally ill person to refuse medical treatment). See also, Cruzan v. Director, Missouri Department Of Health, 497 U.S. 261, 110 S.Ct. 2841 (1990).

End-of-Life Decisions in the Event of No Written Health Care Advance Directive

According to s. 765.401 F.S., in the absence of an advance directive the following individuals are able to act on behalf of an incapacitated² or developmentally disabled patient³:

- A judicially appointed guardian;
- Patient's spouse;
- Adult child or majority of adult children of parent;
- Parent of the patient;
- Adult sibling or majority of adult siblings of patient;
- Adult relative with knowledge and prior care and concern of patient;
- Close friend of the patient; or
- Social worker⁴ or a graduate of a court-approved guardianship program who is approved by the providers Bioethics committee, but who can't be employed by the provider.

The extent to which a health care surrogate or proxy should have authority to make end-of-life decisions when there is no written health care advance directive and family members controvert the end-of-life decision is at the center of a highly publicized and extensively litigated case. See In re Guardianship of Schiavo, 851 So.2d 182 (Fla. 2nd DCA 2003), rev. den.⁵ The case involves the withholding or withdrawal of sustenance and hydration from a woman, Terri Schiavo, who, after suffering a heart attack at the age of 27 in 1990, is in a persistent vegetative state. A medical malpractice lawsuit resulted in a \$1 million settlement in 1993. Approximately five years later, her spouse, Michael Schiavo petitioned the court to determine whether his wife's feeding tube should be removed. That petition initiated a multi-year and ongoing legal battle between Michael Schiavo and Terri Schiavo's parents.

Since Ms. Schiavo never executed a written document expressing her desire for end-of-life care, one of the primary focuses of the debate has been whether there was clear and convincing evidence of what Ms. Schiavo would have wanted to do in her state.

LEGISLATIVE ESTABLISHED PANEL FOR THE STUDY OF END-OF-LIFE CARE

The Legislature established in 1998 the Panel for the Study of End-of-Life Care to conduct a study on end-of-life care. The 22 member panel consisted of representatives from hospice, nursing homes, assisted living facilities, hospitals, physicians, nurses, government officials, and consumers. The Panel traveled the state accepting public testimony on the topics and studied pain management, advance directives, and fiscal and regulatory barriers to good end-of-life care.

The Panel's Recommendations

The Panel's recommendations emphasized the need for reeducation of virtually all segments of society to improve understanding of "what constitutes good end-of-life care and the opportunity to experience a quality life until the very end." The Panel endorsed the following goals for pursuing such an objective:

 The right to refuse treatment and the patient's right to make decisions about his or her care and his or her surrogate's right to carry out the patient's wishes when he or she is no longer capable of decision making;

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² According to s. 765.101, F.S., 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.

³ According to s. 393.063, F.S., "developmental disability" means a disorder or syndrome that is attributable to retardation, cerebral palsy, autism, spina bifida, or Prader-Willi syndrome and that constitutes a substantial handicap that can reasonably be expected to continue indefinitely.

⁴ See s. 765.401, F.S

⁵ Schindler v. Schiavo (In re Guardianship of Schiavo), 780 So.2d 176 (Fla. 2d DCA 2001) (Schiavo I); Schindler v. Schiavo (In re Guardianship of Schiavo), 792 So.2d 551 (Fla. 2d DCA 2001) (Schiavo II); Schindler v. Schiavo (In re Guardianship of Schiavo), 800 So.2d 640 (Fla. 2d DCA 2001) (Schiavo III).

- The right to die without aggressive curative treatment does not equal an obligation to die at any
 age or with any disability, this right is about supporting an individual's right to make choices
 along the life continuum in the context of their values, their beliefs, and their situations;
- The realignment of existing financial resources to appropriately reimburse for palliative care;
 and
- The right of all persons, regardless of insurance status, to be provided access to good end-oflife care.

Issues in End-of-Life Care Identified by the Panel

The Panel provided the following recommendations to the Legislature:

- The Legislature adopt a definition of palliative care similar to that of the World Health Organization
 which defines palliative care as "the active total care of patients whose disease is not responsive to
 curative treatment." Control of pain, of other symptoms, and of psychological, social and spiritual
 problems is paramount. The goal of palliative care is the achievement of the best quality of life for
 patients and their families.
 - Currently, s. 765.102, F.S., defines "palliative care" as the comprehensive management of the physical, psychological, social, spiritual, and existential needs of patients. Palliative care is especially suited to the care of persons who have incurable, progressive illnesses.
- The Legislature should amend the current Patient Bill of Rights to include specific reference to access to pain and palliative care.
 - Currently, the Patients Bill of Rights⁶ does not include a reference to pain or palliative care.
- That it be recognized that every person in Florida has a constitutional and common-law right to direct his or her own medical care, including the right to refuse medical treatment; that this right extends to competent and incompetent persons alike; that the Legislature remove such language as "terminal condition" and "end stage condition" which may represent impediments to the implementation of patients' choices; and that the Florida Legislature remove from Chapter 765, F.S., all language which stands in the way of fulfilling patients' rights.
 - Currently, Chapter 765, F.S., utilizes the terms "end-stage" and "terminal condition."
- The Panel further recommended that only one physician is required to determine whether the medical condition or limitation referred to in an advance directive exists.
 - Currently, s. 765.306, F.S., provides that the patient's attending or treating physician and at least one other consulting physician must separately examine the patient. The findings of each 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.

⁶ See s.381.026, F.S.

HEALTH CARE ADVANCE DIRECTIVES

An advance directive is a witnessed written document or oral statement in which instructions are given by a principal⁷ 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 health care surrogate, a living will, or an anatomical gift made pursuant to the laws of Florida.⁸ Such directives may be made in advance through oral statements made to others or through a living will or other written directive that expresses the person's wishes.⁹ The decision is usually made in fairly general terms because the precise kind of medical treatment cannot be specified without making the advance directive so specific that it runs the risk of failing to apply to various possible situations.¹⁰

A patient has the right to refuse or accept medical treatment, but the advance directive must specifically state the patient's wishes. An advance directive only goes into effect when the patient is unable to make their own decisions.

The American Medical Association lists the following examples of patient wishes that could be included in advance directives as treatment avoidance orders are:

- Do Not Resuscitate (DNR);
- Full Comfort Care Only (FCCO);
- Do Not Intubate (DNI); Do Not Defibrillate (DND);
- Do Not Leave Home (DNLH); Do Not Transfer (DNT);
- No Feeding Tube (NFT); No Vital Signs (NVS);
- No Blood Draws (NBD); and
- Do Not Treat (DNT).

Living Will

A "living will" is a witnessed document in writing voluntarily executed by the principal in accordance with current law, or an oral statement that expresses the principal's instructions concerning life-prolonging procedures.¹¹ A competent adult may make a living will or written declaration and direct the withholding or withdrawal of life-prolonging procedures in the event that such a person is diagnosed as having one of the following conditions¹²:

- An end-stage condition, which is an irreversible condition that is caused by injury, disease, or illness that has resulted in progressively severe and permanent deterioration, and which, to a reasonable degree of medical probability, treatment of the condition would be ineffective.¹³
- A persistent vegetative state, which is a permanent and irreversible condition of unconsciousness in which there is an absence of voluntary action or cognitive behavior, and an inability to communicate or interact purposefully with the environment.¹⁴
- A terminal condition, which is 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.¹⁵

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⁷ The *principal* is the person executing or creating the directive.

⁸ See s. 765.101, F.S.

⁹ See Part III, Ch. 765, F.S.

¹⁰ Meisel & Cerminara, supra note 3, at 7-21.

¹¹ See s. 765.101, F.S.

¹² See s. 765.302 F.S.

¹³ See s. 765.101 F.S.

¹⁴ See s. 765.101 F.S.

¹⁵ See s. 765.101 F.S.

A living will must be signed by the principal in the presence of two witnesses where one can not be a spouse or a blood relative. In the event that a principal is unable to sign the living will, a witness may sign on their behalf in accordance with existing law.

Some health care providers view the living will as a self-executing document upon which an attending physician can carry out the patient's instructions without having to consult with the patient's family, guardians, or close friends. In such cases, it places the person acting for the patient in the position of "approving" the instructions of the patient, as expressed in the living will, and avoids the difficulties presented by family members who are often not emotionally able to direct that life-support be discontinued, despite an incompetent patient's clear instructions.

On the other hand, if a health care provider does not wish to carry out the treatment decisions of a patient or otherwise comply with the patient's wishes regarding life-prolonging procedures, the patient may be transferred to another health care provider.¹⁶

Absence of a Living Will and Decision to Withdraw or Withhold Nutrition and Hydration

In the absence of a living will, a decision to withdraw or withhold life-prolonging treatment may be made by a health care surrogate. Prior to declining health care or life-prolonging treatment the surrogate must be satisfied that there is no probability of the patient recovering or that the patient has an end-stage condition, is in a persistent vegetative state, or the condition is terminal.¹⁷

HEALTH CARE GUARDIAN, SURROGATE, OR PROXY

Health Care Guardian

The court appointment of guardians has long been the traditional arrangement for providing decision making authority for a person who has become incapacitated. A guardian may be authorized to make all decisions for a ward, including health care decisions, and may do so on the basis of the ward's best interests. However, the process is oftentimes cumbersome, time-consuming, and expensive, so that health care surrogates are often used.

Health Care Surrogate

A health care surrogate allows a person, prior to incapacity, to designate someone to act on his or her behalf after he or she becomes incapacitated. A health care surrogate is limited to making only health care decisions and to making decisions based on what he or she has been instructed to do or believes the principal would have done (substituted judgment). The designation must be in writing and witnessed by two adults and signed by the principal, or alternatively, another person to sign on the principal's behalf if the principal is unable sign the instrument. 19

Where a living will provides a presumption of clear and convincing evidence of the patient's wishes, additional conditions must be met by the health care surrogate exercising an incompetent person's right to forgo treatment. They include:

- 1) A determination that the patient does not have a reasonable probability of recovering competency so that the right can be directly exercised by the patient; and
- 2) Any limitations or conditions expressed orally or in the living will, have been carefully considered and satisfied.

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¹⁶ See s. 765.308, F.S.

¹⁷ See s. 765.305 F.S.

¹⁸ See s.765.205, F.S.

¹⁹ See s.765.202, F.S.

Health Care Proxy in Absence of an Advance Directive of an Incapacitated or Developmentally Disabled Patient

Section 765.401, F.S., states that a proxy can be used if there is no advance directive designated or available health care surrogate. A proxy may be selected from a list of specified persons in the following order of priority:

- A judicially appointed guardian;
- Patient's spouse;
- Adult child or majority of adult children of parent;
- Parent of the patient;
- Adult sibling or majority of adult sibling of patient;
- Adult relative with knowledge and prior care and concern of patient;
- Close friend of the patient; or
- Social worker²⁰ or a graduate of a court-approved guardianship program that is approved by the providers Bioethics committee, which can't be employed by the provider.

A proxy must comply with the same provisions as a health care surrogate. However, the proxy's health care decisions must either be supported by a written declaration evidencing the patient's desire for such an action, or if there is no written declaration, determining what is in the best interest of the patient.

Special provisions exist for persons in a persistent vegetative state or a developmentally disabled patient who has not executed an advance directive, or designated a surrogate. If the proxy is a judicially appointed guardian who is not a family or friend, the guardian and the attending physician in consultation with the medical ethics committee of the facility where the patient is located, must conclude the condition is permanent and that there is no reasonable medical probability of recovery.

Conflicts Concerning Health Care Decisions

Section 765.305, F.S., requires that 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 until the case is reviewed.

Currently, s. 765.105, F.S., provides that in the event that a conflict arises concerning the attending physician, health care facility, family, or other interested parties, a judicial intervention may be sought if a person believes:

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

²⁰ See s.765.401, F.S.

MEDICAL PROCEDURES AND THE DECISION MAKING PROCESS ON WITHHOLDING OR WITHDRAWING OF LIFE PROLONGING PROCEDURES

Section 765.306, F.S., requires that in determining whether the patient has a terminal condition, has an end-stage condition, or is in a persistent vegetative state, may recover capacity or 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.

Section 765.404, F.S., states that in the event that a patient in a persistent vegetative state does not have an advance directive or a person willing to act as a proxy, and there is no evidence as to what the patient would have wanted under such conditions, life-prolonging procedures may be withheld or withdrawn in the following circumstances:

- The person has a judicially appointed guardian representing his or her best interest with authority to consent to medical treatment; and
- 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 withholding or withdrawing life-prolonging procedures is in the best interest of the patient.
- In the event that a facility does not have a medical ethics committee, the facility must have an arrangement with the medical ethics committee of another facility or with a community-based ethics committee approved by the Florida Bioethics Network.
- The ethics committee shall review the case with the guardian, in consultation with the person's attending physician, to determine whether the condition is permanent and there is no reasonable medical probability for recovery. The individual committee members and the facility associated with an ethics committee shall not be held liable in any civil action related to the performance of any duties required in this subsection.

Members of the Florida Bioethics Network (FBN) are mostly health professionals, but also include clergy and attorneys. The Networks Executive Advisory Committee is made up of the directors of the state's medical school ethics programs.

In practice, many end-of-life care discussions focus on patients' values and treatment goals rather than on predictions of precise medical conditions and treatment. FBN members have adopted a process very much like that of clinical case consulting in health care organizations:

- Collection of information (talking to principals, assessing key documents, etc.)
- Ethical analysis based on core principals and values relating to valid consent, privacy, justice, access. etc.
- Formulation of recommendations and alternatives.

According to members of the FBN, many incapacitated patients, especially those in a permanent vegetative state, cannot experience hunger, thirst or satiation. While withdrawal of nutrition and hydration is thought of as being uncomfortable or painful, research does not support this and finds that lack of nutrition and hydration may serve as an analgesic for dying patients.

ETHICAL AND MEDICAL PRINCIPALS RELATING TO END-OF-LIFE DECISIONS

There are many things involved in the decision to withhold or withdraw life sustaining treatment,

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including nutrition and hydration. On the one hand there is non-optional palliative care, including provision of nutrition and hydration, to relieve pain and discomfort. On the other hand there is optional medical treatment to prolong life, which a proxy or surrogate can refuse on the patients' behalf. There are different views as to whether nutrition and hydration should be considered ordinary feeding by mouth or an invasive procedure requiring medical protocols for the insertion of a percutaneous endoscopic gastrostomey (PEG) through the stomach wall. An individual's beliefs and morals heavily impact their health care decisions in these matters. The medical profession has developed several policy statements that help address these issues.

The American Medical Association's Principals and Policy Statements

The principles of the American Medical Association (AMA) serve as standards of conduct which define the essentials of honorable behavior for a physician. They include:

- A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights.
- A physician shall, while caring for a patient, regard responsibility to the patient as paramount.
- A physician shall respect the rights of patients, colleagues, and other health professionals, and shall safeguard patient confidences and privacy within the constraints of the law.
- A physician shall respect the law and also recognize a responsibility to seek changes in those requirements which are contrary to the best interests of the patient.

The AMA recognizes that in making decisions regarding the treatment of persons who are severely disabled by injury or illness, the primary consideration should be what is best for the individual patient and not the avoidance of a burden to the family or to society. The AMA establishes that quality of life, as defined by the patients' interests and values, is a factor to be considered in determining what is best for the individual. It is permissible to consider quality of life when deciding about life-sustaining treatment.

The AMA's Council on Ethical and Judicial Affairs defines life-sustaining treatment as any treatment that serves to prolong life without reversing the underlying medical condition. Life-sustaining treatment may include, but is not limited to, mechanical ventilation, renal dialysis, chemotherapy, antibiotics, and artificial nutrition and hydration.

The AMA suggests that physicians should provide all relevant medical information and explain to surrogate decision makers that decisions regarding withholding or withdrawing life-sustaining treatment should be based on substituted judgment (what the patient would have decided) when there is evidence of the patient's preferences and values. In making a substituted judgment, decision makers may consider:

- The patient's advance directive (if any);
- The patient's values about life and the way it should be lived; and
- The patient's attitudes towards sickness, suffering, medical procedures, and death.

If there is not adequate evidence of an incompetent patient's preferences and values, the decision should be based on the best interests of the patient (what outcome would most likely promote the patient's well-being). Even if the patient is not terminally ill or permanently unconscious, it is not unethical to discontinue all means of life-sustaining medical treatment in accordance with a proper substituted judgment or best interest analysis.

American Academy of Hospice and Palliative Medicine Policies on Nutrition and Hydration and End-of-life Care

The American Academy of Hospice and Palliative Medicine (AAHPM) recognizes that dying is an

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expected natural process in the human life cycle. Hydration and nutrition are traditionally considered useful and necessary components of good medical care. Their intent is to benefit the patient. However, when a person is approaching death, the provision of artificial hydration and nutrition is potentially harmful and may provide little or no benefit to the patient and at times may make the period of dying more uncomfortable for both the patient and family. For this reason, the AAHPM believes that the withholding of artificial hydration and nutrition near the end of life may be appropriate and beneficial medical care. Clinical judgment and skill in assessment of individual clinical situations is necessary to determine when artificial hydration and nutrition are appropriate measures.

According to the AAHPM standards, ethical care of patients at the end of life centers on the principals of autonomy, beneficence, and nonmaleficence.

- Autonomy is defined as the quality or state of being self-governing.
- Beneficence is defined as the quality of being kind or helpful or generous.
- Nonmaleficence is the ethical principal of doing no harm, based on the Hippocratic maxim, primum non nocere, first do no harm.

The Academy recognizes that there are great differences of opinion as to how to balance these frequently conflicting principals. Professional integrity must prevail as these principals are weighed and applied to specific clinical situations. The Academy believes there are limits to autonomy, when it conflicts with beneficence toward the patient and society as well as the health care provider. Respect for autonomy includes the right to have interventions withdrawn or withheld upon request of the patient or designated surrogate, thus relieving the patient of interventions he feels too burdensome compared to expected benefits. The withholding or withdrawal of life-sustaining intervention is not considered euthanasia in current ethical and legal contexts.

C. SECTION DIRECTORY:

The bill's preamble provides a wide range of reasons and interests behind the enactment.

Section 1. Creates the Starvation and Dehydration of Incompetent Persons Prevention Act. Sections 2. and 3. Amend ss. 765.106 and 765.107, F.S., to clarify the relation between those sections and the new Act.

Section 4. Amends s. 765.204, F.S., to make technical changes and to reference the new Act.

Section 5. Amends s. 765.305, F.S., relating to procedures in the absence of a living will, to clarify that the new Act limits its provisions.

Section 6. Amends s. 765.401, F.S., relating to the proxy, to clarify that the new Act limits its provisions. In addition, this section creates a precondition of time spent with the incompetent person before a proxy may decide or execute a decision to remove nutrition and hydration.

Section 7. Amends s. 765.404, F.S., relating to persistent vegetative state, to make clarifying changes including the application of the new Act.

Section 8. Creates s. 765.405, F.S., limiting authority to withhold or withdraw nutrition and hydration to only those persons authorized by statute. It also expressly limits the role of judges in such decisions.

Section 9. Provides that the act is remedial and its provisions applicable to every living person, and prospectively to the execution of health care decisions that may have been made prior to the effective date of the act.

Section 10. Provides the act shall take effect upon becoming law.

II. FISCAL ANALYSIS & ECONOMIC IMPACT STATEMENT

A. FISCAL IMPACT ON STATE GOVERNMENT:

1. Revenues:

None.

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2. Expenditures:

Indeterminate; see "D. Fiscal Comments."

B. FISCAL IMPACT ON LOCAL GOVERNMENTS:

1. Revenues:

None.

2. Expenditures:

Indeterminate: see "D. Fiscal Comments."

C. DIRECT ECONOMIC IMPACT ON PRIVATE SECTOR:

Indeterminate; see "D. Fiscal Comments."

D. FISCAL COMMENTS:

The cost of increased reliance on artificial hydration and nutrition may increase health care expenditures. Patients may not have an advance directive, or living will that specifically deals with nutrition and hydration.

III. COMMENTS

A. CONSTITUTIONAL ISSUES:

1. Applicability of Municipality/County Mandates Provision:

This bill does not require counties or municipalities to spend funds or take an action requiring the expenditure of funds. This bill does not reduce the percentage of a state tax shared with counties or municipalities. This bill does not reduce the authority that municipalities have to raise revenue.

2. Other:

The bill represents an exercise of governmental authority in a subject matter area limited by current precedents interpreting the 14th Amendment of the United States Constitution, and the Privacy Amendment, Article I, Section 17, of the Florida Constitution. There are no known state laws regulating end-of-life decisions that have been overturned by any court.²¹ The case law tends to uphold statutory enactments, or to find statutory voids in which an exercise of constitutional or common law rights is permitted under judicial regulation.²² In addition to its substantive provisions, the bill provides legislative intent and public policy findings that evidence compelling government interests sufficient to authorize some infringement on the right to self-determination in end-of-life decision making. The claims in the bill's preamble evoke principles acknowledged in significant case law.²³

The bill also expressly applies the authority of the legislature to occupy the entire field of regulation related to an important liberty interest. In addition, the bill restricts the role of judicial officers who previously have made health care decisions upon the request of a guardian, proxy or other petitioner. These provisions raise the question of where the authority to regulate guardianship ends and where the independence of judicial officers begins. The bill in effect declares that the making of health care decisions, as opposed to reviewing the legality of such decisions once made, is not a function or power of a judicial officer independent from the regulation of law.

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²¹ See, *Cruzan*, 497 U.S. 261, 110 S.Ct. 2841.

See, e.g., *In re Guardianship of Browning*, 568 So.2d 4.

²³ See *Cruzan*, Sats, 379 So.2d 359, and *Krischer v. McIver*, 697 So.2d 97 (Fla. 1997)

B. RULE-MAKING AUTHORITY:

None.

C. DRAFTING ISSUES OR OTHER COMMENTS:

The relationship between "incompetent" and "incapacitated" is not apparent from the text of the bill. However, according to s. 765.101, F.S., "incapacity" or "incompetent" for purposes of chapter 765 both mean the patient is physically or mentally unable to communicate a willful and knowing health care decision.

Currently, Florida Statute recommends the standard form of a living will.²⁴ The form states that in the event an individual is incapacitated and has a terminal illness, end-stage condition, or is in a persistent vegetative state and the attending physician determines that recovery is unlikely, all life-prolonging procedures are to be withheld or withdrawn. Under current statute life-prolonging treatment encompasses artificial nutrition and hydration. Concerns have been raised that the bill may impact current living wills. The original bill might have created a new requirement that living wills should specifically address artificial nutrition and hydration in order to effectively apply to those topics. By removing the word "specifically" from the term "authorizes withholding or withdrawal of nutrition and hydration," the Committee Substitute intends to preserve the force of surrogate designations executed under part II of chapter 765 and of living wills executed pursuant to the part III of chapter 765.

Concern was raised with the original bill that the term "express and informed consent ... in the applicable circumstances" would negate, possible more, general discussions of patients' values and treatment goals. In effect, the provision would have required patients to execute written advance directives to authorize withholding or withdrawal of medically supplied nutrition and hydration. Amendments adopted in the Health Care Regulation Committee resolved some of these concerns. Specifically, the Committee Substitute does not require specificity with respect to a written directive's authorization for removing nutrition or hydration. In addition, the provision for consent outside written directives was revised to require "express" authorization "in applicable circumstances."

Concern has also been expressed that the act of forced nutrition and hydration through invasive means, such as through the gastrointestinal tract would be allowed in this bill, would be contrary to the religious tenets and practices of Christian Scientists. It is unclear at the time of this writing whether any other statutory provision for implied or presumed consent to health care has a religious exception based upon membership in a religious order or group.

The Committee Substitute retains a definition of "express and informed consent" though the phrase was deleted from the bill by amendment in the Health Care Regulation Committee.

IV. AMENDMENTS/COMMITTEE SUBSTITUTE & COMBINED BILL CHANGES

On March 9, 2005, the Health Care Regulation Committee adopted nine amendments sponsored by Representative Proctor. The amendments that were adopted addressed several of the concerns that are mentioned in the "drafting comments section". The amendments are as follows:

Amendment 2-Renames the act to the "Starvation and Dehydration of Incompetent Persons Prevention Act"; removes the wording "persons with disabilities."

Amendment 3-Guarantees the protections of this act to all living persons.

Amendment 4-Provides for more situations in which nutrition and hydration may be withheld or withdrawn when death is imminent or provision of sustenance is harmful.

Amendment 5-Removes the term "specifically" when authorizing the withholding or withdrawal of nutrition and hydration by written directive or surrogate appointment so the provision preserves present living wills.

²⁴ See 765.303 F.S.

Amendment 6-Replaces the phrase "gave express and informed consent" with "expressly authorized" so that a person does not have to know all relevant facts at the time they authorize removal of nutrition and hydration.

Amendment 7-Adds the requirement that a quardian or proxy must be present with the incompetent person for a period of time prior to withdrawing or withholding nutrition or hydration.

Amendment 8-Places limitations on judicial authority and makes chapter 765 the exclusive authority for end-of-life decisions.

Amendment 9-Changes the current retroactive clause, to clarify the bill only applies to past health care decisions which have not been executed prior to the bill becomes law.

Amendment 10-Adds legislative findings and intent.

This analysis is drafted to the committee substitute.

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