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Advance Care Planning*

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Those associated with Project GRACE agree that all adults should be encouraged by their physician(s) and society as a whole to make clear statements, in legally acceptable documents, as to how they wish to be cared for when their health status, as reflected in their quality of life, deteriorates significantly, or if they experience a sudden cardiac arrest.

Thus, addressing end-of-life issues first and foremost requires advance planning.[1, 2] A scenario-specific living will (LW), which is clearly understood by the individual and his/her relatives and caretakers, from family to physicians, is an absolute necessity.[3–5] The following is an outline to help establish such an advance planning document.

Recommendations for Advance Care Planning

- All information and forms related to Advance Care Planning (ACP) should be written in clear, concise English. If the individual for whom the action(s) implies does not readily comprehend English, the document should be written in the language understood by the individual and then translated into English. The document should be easily read by lay persons and, more important, understood by elderly or ill persons. Readily available trained counselors are needed to explain the forms and guide the individual in his/her decision making and finalization of the document.
- The American Medical Association and other health related organizations should lobby for a Medicare/Medicaid code and an insurance reimbursement code for counseling in ACP.
- Patients (i.e., principals) should be required to discuss the document with any close, caring family and/or their appointed surrogate before signing the document. After such discussion, the surrogate should sign and date the document. The Florida Legislature defined a surrogate as any competent adult expressly designated by a principal to make health care decisions on behalf of the principal upon the principal's incapacity.
- The documents and the planning process should be discussed with the patient's primary physician so that the patient's wishes are clear and acceptable to the physician.
- After such discussion(s), if agreeable, the primary physician should acknowledge the content and date of the document.
- If the physician does not agree with the plan(s), the patient should be informed and the reason(s) should be carefully discussed with the patient, close relatives, and any appointed surrogate. If agreement is not reached, the patient should be referred to another physician.
- It should be made clear that any person executing such a document can delete or change his/her wishes at any time. If a person does change his/her wishes, the individual must inform his/her close relative(s), surrogate(s), primary physician(s), and other care givers.
- The document should be more precise than the traditional, vague language of the current statutory LW. The 1999 Florida Legislature reaffirmed that the term "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 health care surrogate, a living will, or an anatomical gift."[6]

It should be noted that any advance directive made prior to October 1, 1999 (when major changes in the Florida Statutes became effective), shall be given effect as executed provided such directive was legally effective when written.

- The form should provide specific choices that a patient may make, with the opportunity to write in specific desires, including a desire to provide organ donations, as the patient sees fit.
- The LW form should be universal and should be acceptable in all 50 states. There should be a federal law guaranteeing this level of acceptance or a model act which is adopted in all states.
- The LW, stating the terms, should be easily accessible via a driver's license, voter registration card, and/or a national computer registry.
- There should be a specific requirement that LWs be posted on the medical chart in a specific location so that it is easy for medical providers and physicians to locate. The Florida Legislative statute states that "the patient's advance directive shall travel with the patient as part of the patient's medical record."

*Project GRACE Advance Care Planning Document may be obtained by calling 813/884-3990 or toll-free number1-877-99GRACE or www.p-grace.org.

- The LW should provide, and the Legislature should support, a waiver of any liability for any physician or any other healthcare provider who renders care or withholds care from a patient, if they reasonably believe that such action is consistent with the patient's wishes as expressed in the LW.
- There should be a penalty for refusing to follow a valid LW.

Recent substantive changes in the Florida laws should enable the wide use of ACP in guiding medical care. Pertinent changes are summarized in Table I. A flow chart for medical decisions regarding advance care planning is provided in Figure 1.

Recommendation for a Universal Living Will

Category I: Defines Loss of Functionality, Terminal Illness, Coma, Permanent Vegetative State

The following are examples of scenarios that apply to conditions of terminal illness. In these situations, the individual has lost the ability to communicate, dress, feed, or clean himself/herself, hold urine, go to the bathroom without assistance, is not self- ambulatory, and is unable to make appropriate decisions about daily living matters.

Terminal illness: Death is expected to occur even with/without medical intervention(s), or condition is irreversible, or there is no reasonable chance of recovery.

Coma: Refers to permanent unconscious deep sleep. There is brain damage, severe enough to render the individual unresponsive and unable to feel or communicate in any way. There is no reasonable chance for recovery by all generally accepted medical standards.

Permanent vegetative state: There is permanent brain damage, severe enough to render the individual unaware of self or the environment. The patient has irretrievably lost the ability to meaningfully appreciate, understand, and communicate appropriately. There is no reasonable chance for significant improvement

Category II: Significant Diseases that Diminish Quality of Life, such as Advanced Senility, Dementia, Massive Stroke, Loss of Speech, Loss of Independence

The following scenarios apply to conditions that, while terminal, do not render the person comatose or in a permanent vegetative state. In these conditions the end of life is near but not imminent. Active intervention is unlikely to improve the length or quality of life materially. Examples of scenarios when these losses may occur are as follows:

Severe dementia, advanced senility and/or advanced stroke with loss of ability to communicate and loss of an independent life: In this person, brain damage has been present for a while, such as with severe Alzheimer's disease or multiple strokes. The brain damage is severe enough to make the individual lose his/her ability to recognize others, interact with them, or make intelligent decisions. The individual is mostly confused, is totally dependent, and has irretrievably lost the qualities which characterized the individual as a person.

It is any condition with total loss of ability to communicate that renders the patient totally and permanently dependent upon others for feeding, personal hygiene, and all daily activities.

End-stage disease: Death is expected in the near future with or without treatment.

- Disseminated cancer not responsive to treatment
- End-stage heart or lung disease, provided heart-lung transplantation is not indicated or feasible. (End-stage heart disease when there is loss of response to maximum medical therapy and requiring repeated hospitalization over the previous 3 months); (end-stage lung disease rendering the patient chair bound and needing oxygen around the clock)
- End-stage infection such as with terminal stages of acquired immune deficiency syndrome (AIDS)
- Disseminated infection with an organism resistant to all available antimicrobials (antibiotics)
- End-stage liver disease when liver transplant is not indicated or not feasible
- End-stage kidney disease in conjunction with advanced heart, lung, or liver disease. Dialysis is either not indicated or unlikely to improve the quality or length of life or has been instituted and has not been effective
- End-stage nervous disorder with near complete total body paralysis, near total dependence with no hope for improvement.

Advanced conditions and disease(s) that diminish the quality of life: Advanced senility, extreme frailty, total dependence, and unbearable and unrelievable pain. These individuals are particularly susceptible to bone fractures, pneumonia, heart attacks, and strokes.

Conditions and findings that make ordinary activities of daily living impossible, such as:

- Tolerate unbearable and unrelievable pain
- Clean oneself
- Feed and hydrate oneself
- Dress oneself
- Control one's bladder and/or bowel
- Communicate and express oneself
- Ambulate independently
- Make decisions about daily living matters.

With each of the medical scenarios, the patient is given the choice whether to forego specific medical interventions including:

- Cardiopulmonary resuscitation (CPR)
- Life support measures such as assisted ventilation and dialysis, surgery, and other interventions unlikely to change the underlying medical condition
- Blood transfusion intended to treat incidental anemia
- Antibiotics aimed to treat a terminal pneumonia or a concurrent infection except for treatment designed to relieve distressing symptoms (e.g., urinary tract infection causing dysuria)
- Tube feeding and hydration.

TABLE I Guide to 1999 changes in Florida's Living Will law

Topic	Old law	Chapter 99-331 new law
Determining capacity of patient	Attending physician and a consulting physician must evaluate patient	Attending physician alone may determine capacity 765.204(2)
Conditions which will activate Living Will	Terminal condition or persistent vegetative state	Terminal condition or end-stage condition, or persistent vegetative state 765.302
Determining patient's condition	Attending physician and consulting physician	Same 765.306
Applicability to person who never had capacity to execute Living Will	Not clear whether Chapter 765 could be applied	Procedures in Chapter 765 do not apply to persons who never had capacity to designate a health care surrogate or execute a living will—765.102(20)
Requirements in the absence of a wriiten Living Will	No requirements specified	Law now specifies additional requirements in the absence of a Living Will. In addition to being in a terminal condition, end-stage condition, or peristent vegetative state, the patient must be both mentally and physically incapacitated with no reasonable medical probability of recovery—765.305(2)(b)
Standard prehospital Do Not Resuscitate Order (DNRO). Department of Children and Family Services (DCFS) Form No. 1896§401.45	Applied only to emergency medical personnel	Now may be honored by: Nursing home staff — 400.142(3) Hospital emergency services personnel — 395.1041(3)(1) Assisted living facility staff — 400.4255(3) Home health agency staff — 400.487(7) Hospice care team — 400.6095(8) Providers of adult family care homes — 400.621(3)
Liability shield for honoring a DNRO	Only applied to emergency service personnel	Expanded to apply specifically to: Nursing home staff — 400.142(3) Hospital emergency services personnel — 395.1041(3)(1) Assisted living facility staff — 400.4255(3) Home health agency staff — 400.487(7) Hospice care team — 400.6095(8) Providers of adult family care homes — 400.621(3)
Authority of health care surrogate to authorize organ donation	No authority	Health care surrogate may authorize organ donation if the patient previously signed a document evidencing his or her intent to donate or indicated such intent on his or her driver's license — 732.912(2)
Organ donation considered a health care decision	Not clear	Law specifically recognizes that the decision to make an anatomical gift is a health care decision — 765.101(5)
Life-prolonging procedures include artificially providing sustenance and hydration	Not clear, generally understood based on case law	Law specifically provides that artificially providing sustenance and hydration are life prolonging procedures — 765.(0)(10)

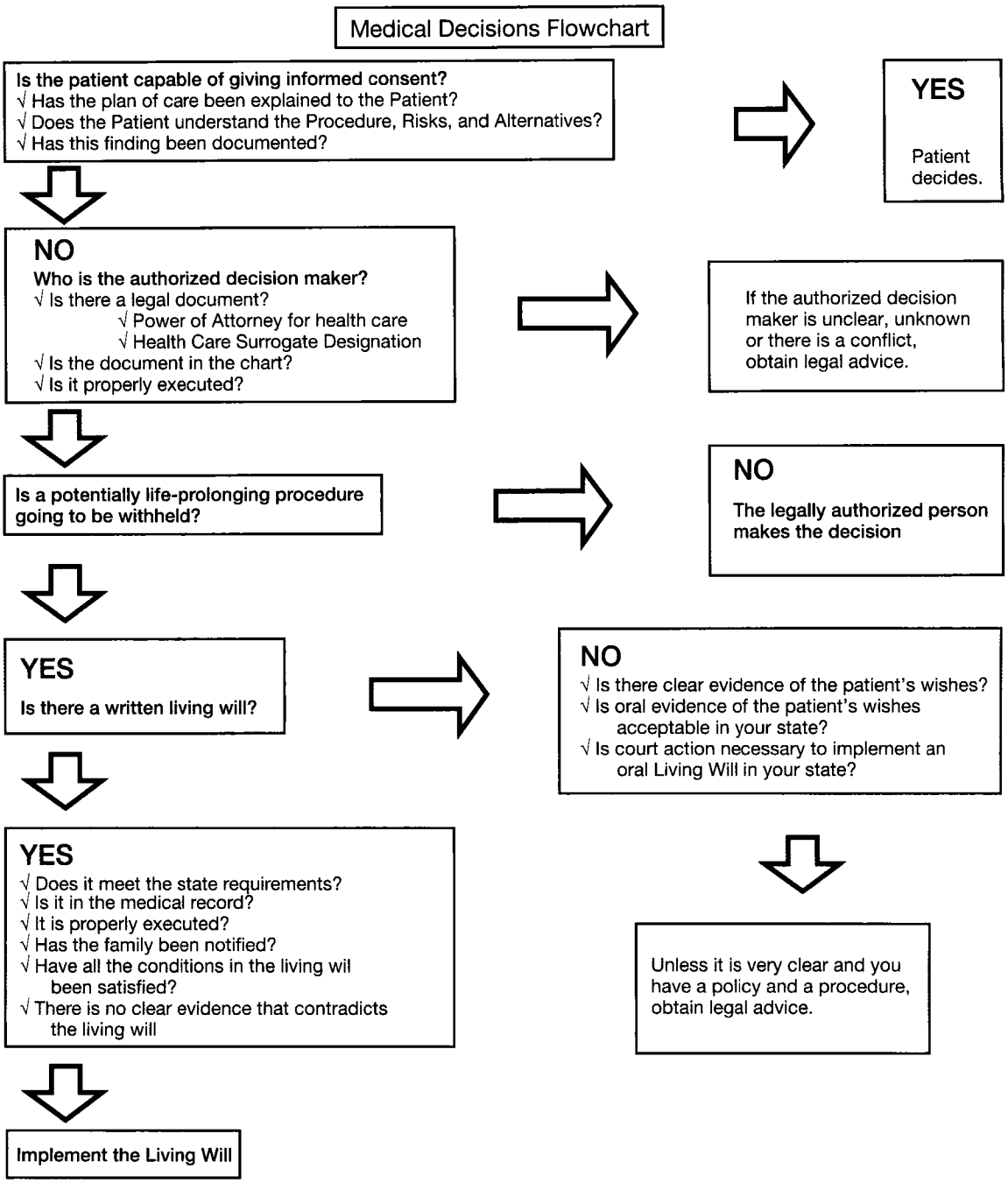

FIG. 1 A Medical Decision Flowchart to guide physicians caring for patients nearing their death. Copyright © 1999 M.D. Geldart, Esq. Reprinted with permission.

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6. Fl. Stat. 765.101(1)