

**PANEL FOR THE STUDY  
OF  
END-OF-LIFE CARE**

**Final Report**

**Submitted by:**

**Panel for the Study of End-of-Life Care  
August 1st, 1999**

**Administered by:**

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August 1, 1999

To: The Honorable Jeb Bush, Governor  
The Honorable Toni Jennings, Senate President  
The Honorable John Thrasher, House Speaker

The 1998 Florida Legislature created, in CS/CS/HB 3387, the Panel for the Study of End-of-Life Care. This 22-member panel was directed to study issues related to the care provided to persons as they near the end of their lives. In particular, the group was requested to consider the issues of pain management, advance directives and regulatory and fiscal barriers and incentives that impact end-of-life care. I have been honored to serve as Chairman of this Panel and help facilitate its work on this extremely important area of public policy. The Panel held meetings across the state and received important public input on these issues.

As a result of the Panel's work and recommendations, the legislature passed legislation this year that addressed a number of the issues raised in the Panel's interim report. CS/CS/SB 2228 was signed into law by Governor Bush on June 11, 1999. This law will help Florida's citizens receive more compassionate, dignified care as they near the end of their lives.

Yet, as a state, there is still much we need to do. The Panel, post-legislative session, continued its work to assess the impact of the new legislation, help expedite its implementation and make further recommendations regarding end-of-life care. Summaries of this work and recommendations are contained herein. Our hope is that through continued public and legislative debate, discourse on end-of-life care will be kept very much alive.

As Chairman, I would like to acknowledge the tireless work of those who served as Panel members, alternates and advisors without whose wisdom and genuine compassion we could not have accomplished our goals. The Pepper Institute on Aging and Public Policy and its Director, Dr. Melissa Hardy, also deserve special recognition for their vision, dedication and commitment to the Panel's mission.

Additionally, on behalf of the entire panel, I thank the House and Senate committee staff whose extraordinary work guided CS/CS/SB 2228 through the legislative process.

Finally, the Panel would like to extend our deepest thanks and respect to Governor Bush and the members of the Florida House and Senate. Your commitment to this topic is a true testament to your level of caring and compassion for your constituents and the people of Florida.

Though our work as a panel is complete, I, like my counterparts on the Panel, remain dedicated to ensuring that those facing this difficult time of life receive the very best care possible. Thank you for allowing us to serve.

Sincerely,

Robert G. Brooks, M.D.  
Chairman, Panel for the Study of End-of-Life Care  
Former Member, Florida House of Representatives, District 35  
Secretary, Florida Department of Health

## Executive Summary

The Panel for the Study of End-of-Life Care was constituted according to the membership provisions in the enabling legislation and given its specific charge by the Florida Legislature (CS/CS/HB3387). The Panel was directed to study issues related to the care provided to persons at the end of life (EOL) and to:

- (1) Develop methods to ensure that pain management is a goal in each health care setting;
- (2) Identify barriers that hinder health care professionals from providing satisfactory pain management and palliative care;
- (3) Determine whether mandatory education in pain management and palliative care should be required as a condition for licensure or relicensure of health care professionals;
- (4) Assess the current use of advance directives and determine whether changes are necessary to ensure that, once prepared, advance directives will be honored in any health care setting;
- (5) Study the regulatory and financial incentives that influence the site or setting of care and of care providers.

By holding public hearings around the state and encouraging the involvement of advisory groups throughout the state, the Panel has facilitated a comprehensive and integrated approach to the improvement of end-of-life care. For the first time, all these interested parties, in conjunction with representatives of the general public, are engaged in a dialogue on end-of-life issues with the shared goal of improving end-of-life care for the people of Florida.

After considering the important accomplishments of the 1999 Legislative session, panel members identified unresolved problems that present barriers to the provision of quality end-of-life care and implementation of patients' choices. To address some remaining issues, the Panel recommends that:

- ◆ The Legislature create incentives for health and elder care providers and for publicly accessible media such as the press and public radio and television designed to encourage public dialogue about advance directives and end-of-life care options.
- ◆ The Legislature encourage the ongoing development of innovative end-of-life educational programs and standardized training for all health care providers.
- ◆ The Legislature encourage professional boards to accept standardized care training, including, but not limited to pain management; advance directives, do-not-resuscitate orders, and living wills; hospice care; bereavement counseling; and clinical and ethical decision making.
- ◆ The Legislature recommend that professional organizations representing physicians, nurses, social workers, pharmacists, administrators of health care facilities, clergy and lawyers develop strategies to promote and provide incentives for participation in end-of-life training and that these professional organizations incorporate end-of-life education in their on-going educational activities.

- ◆ The survey conducted by the chancellor of the state university system's work group on end-of-life curriculum should include a review of required health care texts and classroom instruction for inclusion of pain and palliative care instruction and clinical and ethical decision making in end-of-life care and make recommendations for a basic end-of-life curriculum through the respective Boards of medicine, nursing, social work, pharmacy, and other health care disciplines.
- ◆ Continuing education in end-of-life care may be substituted for any of the current mandatory continuing education requirements (not just HIV/AIDS), when these requirements have been met in previous cycles, for professions that include but are not limited to, physicians, nurses, social workers, pharmacists, administrators of health care facilities, clergy and lawyers.
- ◆ In facilities and organizations licensed under Florida Chapter 400 and Chapter 395, the appropriate regulatory agency recognize programs that demonstrate excellence in care at the end of life.
- ◆ The Legislature remove regulatory barriers to access of appropriate hospice service including consultation and early intervention programs for the enhancement of end-of-life care.
- ◆ Insurance plans, managed care plans, and Medicaid include advance care planning as a reimbursement-coded service when provided by professionals trained in end-of-life and palliative care.
- ◆ The Legislature establish a working group made up of a representative from the Florida Legislature, staff representation from the House and Senate Appropriations committees, the Agency for Health Care Administration, the Department of Elderly Affairs, the Department of Health, and representatives from the respective provider associations. This working group should be charged with:
  - a. Examining reimbursement methodologies for end-of-life care (such as consultative hospice service and a Medicaid case-mix reimbursement of palliative care);
  - b. Developing recommendations for incentives for appropriate end-of-life care;
  - c. Enabling all providers along the health-care continuum to participate in an excellent standard of end-of-life care.
- ◆ 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."
- ◆ The Legislature amend the current Patient Bill of Rights to include specific reference to access to pain and palliative care.

- ◆ Pain management, when provided in full compliance with the Chapter 30 “Intractable Pain Statute,” should be construed as meeting the standard of medical care. Nothing in this recommendation should be taken to promote or condone physician-assisted suicide or euthanasia.

- ◆ The Florida legislature adopt language to promote the following recommendations:

Professional education:

- a. Encourage medical, nursing, social work, and pharmaceutical schools throughout the state to review and implement curricula designed to train providers in principles of pain management and palliative care;
- b. Encourage development of materials and courses designed to educate practicing health-care professionals on appropriate standards on pain management and palliative care;
- c. Promote specialist training programs (palliative care fellowship program) for physicians in each of Florida’s medical school;
- d. Promote specialist training for nurses, nurse practitioners, pharmacists, social workers to create a cadre of palliative care specialists;
- e. Promote increased and earlier referral to hospice programs for appropriate patients;
- f. Establish programs on end-of-life care at one or more centers to serve as centers of research and policy analysis on end-of-life care in the state.

Public Education:

- a. Create a statewide education campaign to improve understanding of palliative care, to enhance access to hospice and palliative care services and to promote understanding of the need for advance care planing and advance directives.
  - b. Create culturally sensitive education programs to improve end-of-life care in minority communities.
- ◆ Where appropriate, the Agency for Health Care Administration, the Department of Elderly Affairs, and the Department of Health should be directed to develop or adopt reasonable approaches to ensuring the effectiveness of pain and palliative care strategies.
  - ◆ Health care facilities, other organizations, and providers caring for people at the end of life should develop strategies to provide access to palliative care. Standards for pain management, management of other distressing clinical symptoms at the end of life, advance care planing, and systems to attend to emotional and spiritual needs should be in place or available in all settings which care for seriously ill patients.
  - ◆ Health-care boards adopt rules concerning guidelines for pain management and that these boards develop and promote educational programs to disseminate information regarding these rules and practices.

- ◆ The Florida Legislature designate specific funding of studies to determine the clinical needs, costs, and services available to Floridians dying at home, hospice, hospital, assisted living centers, nursing homes, and those without health-care insurance.
- ◆ 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 all language which stands in the way of fulfilling patients’ rights.
- ◆ The Legislature (as well as private sources) encourage and, where appropriate, fund efforts by state agencies, professional societies, universities, community colleges, and civic organizations to educate consumers, the general public, and health care providers about patients’ advanced care planning. This education should include how to implement the patient’s unique wishes with sensitivity to the patient's cultural heritage.
- ◆ The Legislature continue to encourage creation of a standardized and portable do not resuscitate (DNR) form that can be used in all patient settings. They should also enact procedures necessary to facilitate the effective use of this form.
- ◆ The phrase “mentally and physically” be deleted from Chapter 765.
- ◆ Only one physician be required to determine whether the medical condition or limitation referred to in an advance directive exists.



# FINAL REPORT

## *Panel for the Study of End-of-Life Care*

### Introduction

The demographics of a rapidly aging Florida population coupled with strides in medical technology have pushed end-of-life (EOL) medical issues to the forefront of public attention. Today most Americans die at an advanced age from four diseases: heart disease, cancer, cardiovascular accident or stroke, and chronic obstructive lung disease. Patients are likely to live months, even years with these illnesses that will eventually lead to their deaths.

A century ago, most Americans died from infection, accidents, childbirth, and childhood diseases before they reached age 50. This contrast should be reflected in the medical models of the two time periods—an earlier emphasis on curative care evolving to a dual emphasis on curative and comfort care. However, attitudes and behaviors about death and dying have not caught up with modern health care technology. The early century experience of dying quickly at home in the arms of family members has been replaced with a slow death in hospitals or nursing homes.

Because of the size and diversity of Florida's population and the diversity of providers involved in EOL care, the development and implementation of a statewide end-of-life (EOL) care initiative requires substantial coordination. The legislative mandate creating a statewide Panel for the Study of End-of-Life Care provided the framework to address needs in current care practices. During the past year, the Panel spearheaded changes in legislation, regulations, education (both among consumers and providers), and care practices that addressed the inadequacies of EOL care in Florida.

### Florida's Population

During the last 50 years Florida's population has grown by more than 400%, making Florida the fourth most populous state. Florida's population is also highly diverse with regard to race/ethnicity,<sup>1</sup> urban/rural areas of residence, religious practices,<sup>2</sup> and cultural traditions. Florida has the largest proportion of elderly residents, the third largest incidence of AIDS and the fourth highest death rate from AIDS, the highest death rate from cancer, and one of the highest death rates from heart disease and chronic obstructive pulmonary disease in the nation.

In 1996, 152,697 Florida residents died. The death rate for women (both white and nonwhite) increased, while the death rate for white and nonwhite men declined. Of total deaths, 89%

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<sup>1</sup> According to the 1990 Census, Florida's population consisted of 73.3% nonhispanic whites, 14.7% nonhispanic nonwhites, and 12% hispanics.

<sup>2</sup> Fewer than half of Florida's population are adherents of either the Christian or Jewish religions (U.S. Bureau of the Census, *Statistical Abstract of the United States, 1997*, (117 edition.) Washington, DC, 1997, Table No. 87.

involved whites and 11% involved nonwhites. Heart disease was the leading cause of death (approximately one-third) and cancer was the second leading cause, accounting for almost one-fourth of the deaths.<sup>3</sup> HIV was the third leading cause of death among nonwhites; the HIV death rate among nonwhite men was higher than the combined rates for white men and white and nonwhite women. Suicide was one of the top 5 causes of death for people aged 50 to 54; it is one of the top ten causes of death among 55-64 years olds. Among those 65 and older, the relative ranking of suicide deaths is supplanted by prominent disease-related causes.<sup>4</sup>

Nationally, approximately 57% of deaths occur in hospitals (excluding those dead on arrival), 17% die in nursing homes, 20% in residences, and 6% elsewhere (including DOA).<sup>5</sup> In Florida, approximately 50% of all deaths occurred in hospitals, 25% in a residence, and 20% in nursing homes. Among those 65 and older, 32.3% of patients who died were under hospice care, compared to a national average of 18%; 25% of those younger than age 65 were hospice patients. In 1997, Hospice served 46,608 patients; the hospice census taken on July 1<sup>st</sup>, 1997 recorded slightly more than 1800 nursing home residents and over 5,000 private home patients receiving hospice care on that day. Thousands of others were served in hospice supportive care, community and bereavement programs.<sup>6</sup> Hospice admissions were most often among cancer patients, although hospice care can be appropriate for people of all ages and diagnoses. During a 12-month interval, three times as many cancer patients aged 65 and older (compared to those younger than 65) were admitted, and three times as many cancer deaths occurred among the older group. Hospice admissions of older patients for other conditions were almost 7 times the rate for younger patients, with a ratio of deaths among older to younger patients of 3.5:1. Florida leads the nation in the number and percent of people served by Hospices.

Patient satisfaction data suggests that hospice organizations have been better able to provide pain management to patients and that patients and families are more satisfied with their involvement in their care when in Hospice. Research indicates that the cost of hospice care in Florida results in an overall savings of Medicare dollars; a Lewin study reports that Medicare saves \$.52 for every dollar spent on hospice care.<sup>7</sup> Unfortunately, many people are referred to Hospice too late to receive maximum benefit. Such late referrals result in unnecessary suffering for patients, as opportunities for quality care at the end of life are lost. Late referrals also result in significant financial costs to payers.<sup>8</sup> Florida includes several of the hospital referral regions in which

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<sup>3</sup> Respiratory cancer was the most common cancer among white men, nonwhite men, and white women; cancer of the digestive organs and peritoneum was the most common among nonwhite women. Cancer was the leading cause of death for 45-54 and 55-64 year olds, accounting for 36.1% of death for those age groups (Florida Vital Statistics Annual Report, 1996).

<sup>4</sup> The suicide death rate for men is more than four times the rate for women, and death from suicide is 2.5 times as likely among whites as among blacks. In 1996, 35-44 year olds had the largest number of suicide deaths (468) followed by those aged 75 and older (352 deaths). The age pattern of suicides peaks at the 35-44 age range, declines among successive age groups and then increases again among the oldest.

<sup>5</sup> Data (1992) are from the Institute of Medicine, Section 2, page 7, June of 1997.

<sup>6</sup> Data are from the Hospice Program Needs Projections Report, Agency for Health Care Administration, February 6, 1998.

<sup>7</sup> Health Care Financing Administration National Hospice Study; Medicare Hospice Benefit Program Evaluation (Abt); Lewin-VHI Analysis of Cost Savings of the Medicare Hospice Benefit.

<sup>8</sup>The Dartmouth Atlas of Health Care, 1998.

under highly diverse conditions, and sufficiently sensitive to the cultural differences of patients and their families requires that all parties be willing to work together to forge solutions. It is within this setting that the Panel began its work.

## **Broad-Based Dialogue and Coordination**

A central goal of the Panel was to provide a structure for dialogue among the various groups that are involved in end-of-life care decisions and practices. The Panel was not the first group to engage these issues. On the contrary, Florida has had a number of groups addressing different sets of issues among different constituencies. Generating interest in these issues is not the problem. Coordinating action, promoting discussion across *all* these groups, widely disseminating information, and providing a focal point for devising solutions are the challenges that we face. Providing training for those who select themselves into the audiences is not sufficient. We must create a need for providers to learn and to change, and we must ensure that the information they are receiving through the educational programs is accurate and up-to-date. Meeting this goal requires that health care and professional organizations along with state regulatory agencies are involved in both design *and* implementation.

## **Current Situation**

In its 1998 session, the Florida Legislature directed that a Panel for the Study of End-of-Life Care be established (Ch. 98-327, L.O.F.). After two initial organizational meetings that were held in Tallahassee, the Panel held meetings coupled with public hearings around the state. Members of the public frequently voiced frustration over the inability of individuals to have their treatment wishes honored and lamented the absence of statewide procedures for executing and honoring do-not-resuscitate orders (DNROs) across the multiplicity of healthcare settings. They were confused by the variety of forms and lack of easily accessible public information that clearly explained their rights, their options, and the appropriate procedures for implementing their rights. Providers noted that palliative care, pain management, discussion of death, and end-of-life care received little attention in established curricula. As the population continues to age and medical technology improves, this deficiency in training and education becomes increasingly problematic. The fact that our society shuns an open discussion of death makes communication between providers and patients as well as between patients and their families difficult.

**Education.** The medical literature has cited inadequate knowledge of pain management, symptom control, and palliative care among health care professionals as a key barrier to good end-of-life care.<sup>11</sup> In 1994, Florida's Pain Management Commission recommended that pain management be an integral component of the curricula of schools for health care professionals, including medical, osteopathy, chiropractic, nursing, and pharmacy schools.

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<sup>11</sup> Field, M.J., and Cassel, C.K. (Eds.). (1997). *Approaching death: Improving care at the end of life* (Report of the Institute of medicine Task Force). Washington, DC: National Academy Press.

This expansion of professional curricula would be an important step in improving clinical training in end-of-life care, but pain management is not the only component of end-of-life care that needs to be addressed in these professional schools. A recent study of nursing textbooks found that only 2% of the content of these textbooks was related to end-of-life care.<sup>12</sup> Texts contained inaccurate information about the concept of addiction and undertreatment of pain. A similar situation exists in medical texts. A review of basic medical texts reported that the space devoted to palliative care was limited to two and a half pages; the terms “palliative care,” “comfort care,” and “hospice” were not listed in the index.<sup>13</sup> Many physicians are not familiar with advance directives, the regulations governing advance directives, the use of hospice, or the protocols involved in providing good palliative care.

Finally, health care providers are often untrained in the skills of communication and teamwork. The hierarchy of medicine has traditionally taken precedence over teamwork strategies in the delivery of care. An increase in the number of managed care plans and a growing appreciation of the organizational complexities of providing quality care have underscored the need for effective communication, coordination and cooperation among clinicians who are jointly involved in patients’ treatment.

## Legal and Regulatory Context<sup>14</sup>

Members of the Elder Law Section of the Florida Bar provided the Panel with research on the legal issues involved in recognizing advance directives. Both statutory and case law at the federal and state level establish the right of legally competent adults to make health care decisions, including decisions about the amount, duration, and type of medical treatment they wish to receive. Grounded in Art. I, § 23 (Right of Privacy) of the Florida Constitution, the Florida Supreme Court has held that a person’s fundamental right of self-determination encompasses the right to make choices about medical treatment. Through a sequence of decisions, the right to refuse medical treatment was firmly established for:

- a competent but terminally ill person (*Satz v. Perlmutter*, 379 So.2d 359 (Fla. 1980));
- an incapacitated terminally ill person (*John F. Kennedy Memorial Hospital, Inc. v. Bludworth*, 452 So. 2d 921 (Fla. 1984));
- a competent but not terminally ill person (*Wons v. Public Heath Trust of Data County* (541 So.2d 96 (Fla. 1989));
- and an incapacitated but not terminally ill person (*In re Guardianship of Browning*, 568 So. 2d 4 (Fla. 1990))

As the court stated:

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<sup>12</sup> Ferrell, B, R. Virani, and M. Grant. “Analysis of End-of-Life Content in Nursing Textbooks.” ONF, 26(5), 1999:869-876.

<sup>13</sup> Quill, T. and J. Billings, (1998). Palliative care textbooks come of age. *Annals of Internal Medicine*, 129, 590-594.

<sup>14</sup> A more extensive analysis of the relevant law and legislative history is provided in Carter, Matthews, and Peters, *Senate Staff Analysis and Economic Impact Statement of CS/CS/SB 2228*, April 15, 1999. This discussion draws on their analysis as well as personal communications from Meta Calder, Esq., Department of Elder Affairs as cogent summary statements of the major issues.

Our cases have recognized no basis for drawing a constitutional line between the protections afforded to competent and incompetent persons. Indeed, the right of privacy would be an empty right were it not to extend to competent and incompetent persons alike (*Browning* at 12).

In addition, the Court recognized four state interests which may, on a case-by-case basis, override this constitutional right with respect to health care decisions which would result in the person's death. They are: (1) the preservation of life, (2) the protection of innocent third parties, (3) the prevention of suicide, and (4) maintenance of the ethical integrity of the medical profession (*Browning* at 12).

Chapter 765, Florida Statutes, provides a procedure for mentally capacitated individuals to make health care arrangements to ensure their wishes are followed if they become incapacitated. Advance directives, legal documents that must be witnessed to be valid, are required to implement such arrangements. Advance directives may be either written or oral expressions of patient wishes regarding treatment or other aspects of health care.

**Advance Directives.** The use of advance directives to direct treatment is based in the principle of "substituted judgment." Under this principle, the patient's right to direct treatment may be exercised by an authorized person (e.g., a health care surrogate) who acts in a manner consistent with the patient's wishes. When a person has become incapacitated, the Court established a procedure for a surrogate or proxy, acting on the basis of 'substituted judgement' to exercise an incompetent patient's right to refuse treatment. When a patient has previously expressed his/her wishes with respect to medical treatment, the surrogate/proxy must:

1. determine that the patient executed any document knowingly, willingly, and without undue influence, and that the evidence of the patient's oral declaration is reliable;
2. be assured that the patient does not have a reasonable probability of recovering competency so that the right can be exercised directly by the patient; and
3. take care to assure that any limitations expressed whether orally or in the written declaration have been carefully considered and satisfied (*Browning* at 15).

In 1992, these provisions were incorporated into F. S. 765 for patients with a terminal illness. However, the Court did not include terminal illness as a requirement for executing a patient's advance directives. The Panel recommended in its Interim Report that these provisions not be restricted to terminally ill patients. As noted in the Senate analysis to SB2228, "the right of an incapacitated but not terminally ill person to refuse medical treatment" was established *In re Guardianship of Browning*, 568 So.2d 4 (Fla.1990) (1999, page 2, note 1). The fact that Estelle Browning's living will expressed that treatment was to be discontinued when she had a "terminal condition" was instead treated by the court as a specific condition of her will which must be considered (see point (3) above). As stated by the court:

In this instance, Mrs. Browning's wishes were conditional. She indicated that her decision to refuse treatment was limited to a time when she had a 'terminal condition' from which her attending physician determined that there could be 'no recovery' and that 'death (was) imminent' (*Browning* at 17).

The Panel's recommendation of January 1999 was designed to bring into conformity Florida Statute and Florida case law by allowing individuals to choose the conditions under which their advance directives should apply. Although the *option* of limiting advance directives to the stage of terminal illness would continue to be available, such a limitation should not be mandatory. The Panel, prompted by consumer objections to this requirement, proposed a change in the statute. This recommendation proved to be a controversial one.

**Do-Not-Resuscitate Orders.** Cardiopulmonary resuscitation (CPR) was developed in the 1960s to treat witnessed cardiac arrest in patients suffering from accidents or acute coronary events (e.g., acute myocardial infarction). CPR includes closed chest massage and mouth to mouth ventilation, endotracheal intubation, ventricular defibrillation including the use of automatic external defibrillators (AEDs), administration of cardiac resuscitation medications, and related emergency medical procedures applied to a person who is in cardiac or respiratory arrest. It does not include the Heimlich maneuver or other emergency procedures applied to a person who is still breathing and has a heartbeat.

As the provision of emergency medical services has grown exponentially, the use of this procedure has also expanded. CPR is now universally administered in almost all instances of cardiac arrest regardless of the diagnosis or prognosis of the patient. As a consequence, the actual survival rate following the administration of CPR, particularly among the sick and elderly is relatively low. While survival rates after CPR for healthy, young adults with unexpected cardiac arrest due to trauma or surgery may be as high as 70%, the probability of an elderly, frail nursing home resident being successfully resuscitated ranges between 1% and 5%.<sup>15</sup>

Although commonly referred to as “do-not-resuscitate” orders, a recent shift in terminology favors the terminology—“do-not-attempt-resuscitation (DNAR).” More than a quibbling over semantics, the purpose of this newer terminology is to underscore the fact that, for certain subpopulations and in certain categories of circumstance, attempts at resuscitation fail. Whereas the use of the phrase “do not resuscitate” implies that initiating the procedure leads to resuscitation, use of the phrase “do not attempt resuscitation” makes clear that many attempts at resuscitation fail. Further, in some cases in which resuscitation is accomplished, the patient is left with severe mental impairment. Given that DNRO is the most common terminology in use, this report remains consistent with that convention. However, panel members support the newer terminology—do not attempt resuscitation—and believe that a common and precise terminology of procedures and regulations is a goal the Legislature should pursue.

In the same year that chapter 765 was re-written (1992), chapter 401, F.S. was also revised. This revision addressed out-of-hospital emergency medical care and permitted EMTs and paramedics to not attempt resuscitation if presented with an order not to resuscitate signed by the patient's physician (see Ch. 92-78, L.O.F.). Chapter 401 also provides liability protection to personnel who act on the basis of such orders. Without the signed order, emergency personnel are duty-bound to attempt resuscitation.

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<sup>15</sup> Zweig, Steven C., Cardiopulmonary Resuscitation and Do-Not-Resuscitate Orders in the Nursing Home, *Archives of Family Medicine* 1997;6: 424-429.

Standard in-hospital patient care includes the use of a physician issued 'no-code,' another common terminology for an order not-to-resuscitate. Without such orders, resuscitation is routinely attempted. Because these orders are viewed as being within the treatment discretion of licensed physicians, such orders do not require patient consent nor do they require a diagnosis of terminal illness provided the physician determines an attempt to resuscitate would be medically futile. As a matter of practice, however, most such orders are issued in consultation with or at the expressed direction of the patient.

The Department of Health is responsible for developing regulations and procedures relating to emergency services. They designed the form that is currently in use. These out-of-hospital orders must be on a written yellow-colored form entitled, "*Prehospital Do Not Resuscitate Order Form, DH 1896.*" DNROs must include the signature of the person's attending physician; the attending physician must attest that another physician has been consulted and that the patient has a terminal condition. In addition, the document must include the properly witnessed signature of the patient or the patient's surrogate, proxy, or guardian.

In its Interim Report, the Panel argued that the current DNRO procedures (and the required use of the yellow form) constituted a barrier to fulfillment of patient wishes. Because the yellow DNRO form is not honored in alternative health care settings (the liability protection afforded in chapter 401 does not transfer to other medical personnel in hospitals, nursing homes, and hospices), other health care providers use traditional physician issued do-not-resuscitate treatment orders. Consequently, DNRO forms tend to be site-specific; whenever a patient is transferred from one health care setting to another, the DNRO must be reissued.

## **The Panel for the Study of End-of-Life Care**

The Panel for the Study of End-of-Life Care was established by 1998 legislation, CS/CS/HB 3387 (see Appendix I). The Panel was housed and staffed by the Pepper Institute on Aging and Public Policy, 207 Pepper Center, 636 W. Call Street, Florida State University, Tallahassee, Florida 32306-1121. Melissa A. Hardy, Ph.D., Director of the Pepper Institute on Aging and Public Policy and Professor of Sociology, served as Executive Director of the Panel.

### **Legislative Mandate**

According to legislative mandate, the Panel's charge was to study the issues related to care provided at the end of life. Issues considered by the Panel included:

- a) Methods to ensure that pain management is a goal in each health care setting;
- b) The identification of barriers that hinder health care professionals from providing satisfactory pain management and palliative care;
- c) Whether mandatory education in pain management and palliative care should be required as a condition for licensure or relicensure of health care professionals;
- d) The current use of advance directives, to determine whether changes are necessary to ensure that, once prepared, advance directives will be honored in any health care setting;
- e) The regulatory and financial incentives that influence the site or setting of care and or care providers.

The Panel was also charged with holding hearings to receive public testimony as deemed appropriate. The Panel held seven public hearings throughout the state of Florida to take public testimony on issues related to end-of-life care.

### **Appointment Procedures**

The composition of the Panel was intended to bring policymakers and ethicists, professionals and consumers, politicians and service providers, regulators and educators, administrators and practitioners to the table. The appointment of Panel members was conducted according to legislative mandate which stipulates that the 22 appointments be made as follows:

- Two persons representing hospice organizations and one consumer, appointed by Florida Hospices and Palliative Care, Inc. (Samira K. Beckwith; Mary Labyak; Jack Gordon, alt. David Abrams);
- Three persons representing nursing homes and assisted living facilities; two appointed by the Florida Health Care Association and one by the Florida Association of Homes for



the Aging (LuMarie Polivka-West; Dr. Howard Tuch, MD; Marshall Seiden, alt. Molly McKinstry);

➤ Three persons representing hospitals, one each appointed by the Florida Hospital Association, the Florida League of Health Systems, and the Association of Community Hospitals and Health Systems of Florida, Inc. (Dr. Susan White, alt. Bill Bell; Belita Moreton; Joan Fulbright);

➤ One person each appointed by the Florida Medical Association (Dr. Alvin Smith, MD), the Board of Medicine (Dr. Gary Winchester, MD, alt. Dr. Louis C. Murray, MD), the Board of Osteopathic Medicine (Dr. Robert Panzer, DO, alt. Dr. Archie H. McLean), The Florida Bar (Kenneth Rubin, alt. Mary Alice Ferrell), and the Florida Nurses Association (Cathy Emmett, alt. Dr. Georgie C. Labadie);

➤ One member appointed by the President of the Senate (The Honorable Ron Klein, alt. Kelly Skidmore);

➤ One member appointed by the Speaker of the House (The Honorable Dr. Robert Brooks, MD);

➤ One person representing the Commission on Aging with Dignity (Jim Towey, alt. Jackie Roberts);

- ➤ Two persons appointed by the Pepper Institute on Aging and Public Policy at FSU, including a member of the clergy (Dr. Marie E. Cowart, alt. Dr. Penny A. Ralston; Dr. Leo Sandon);

➤ One person representing the Health Quality Assurance Division of the Agency for Health Care Administration (Marshall E. Kelley, alt. Dr. Susan Acker);

➤ The Secretary of Elder Affairs, and one consumer representative appointed by the Secretary (Secretary E. Bentley Lipscomb<sup>16</sup>, alt. June Noel<sup>17</sup>; Stan Godleski).

Dr. Bob Brooks was elected Chairperson of the Panel and E. Bentley Lipscomb was elected as Deputy Chairperson.<sup>18</sup> The full list of Panel Members, Alternates, and Advisory Board Members is included in Appendix 2. Because some of the members of the panel were organizational appointees and because the panel maintained a demanding schedule of meetings, the composition of the panel was amended with the change in administration that occurred as a result of the November 1998 election.

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<sup>16</sup> As Secretary for the Department of Elder Affairs, Mr. Lipscomb served as a member and as Deputy Chair of the Panel through December 1998. Thereafter he was replaced by the newly appointed Secretary, Dr. Gema Hernandez.

<sup>17</sup> June Noel, former Deputy Secretary of the Department of Elder Affairs served with the Panel through December 1998. She was replaced by the Interim Deputy Secretary, Carl Littlefield, and then by Meta Calder, J.D. who acted as alternate for Secretary Hernandez.

<sup>18</sup> At the January 20<sup>th</sup> meeting, Dr. Marie Cowart was elected to be the new Deputy Chair of the Panel and Dr. Brooks became the alternate member for the Florida Osteopathic Medical Association.

## Panel Activities

**Meeting attendance.** Attendance by the Panel member or the alternate member during a majority of Panel meetings was required to retain voting rights. The organizations receiving legislatively mandated representation on the Panel were responsible for appointing alternate delegates, and Panel members were responsible for briefing their alternates.

**Work Groups.** It was determined that the Panel would act as a committee of the whole but be divided into work groups with specific work topics. After discussion as to composition and focus of work groups, it was agreed by acclamation that they be linked to the topics specifically included in the legislation (listed above):

Group 1 would cover topics in sections a, b, and c (pain management points).

Group 2 would cover topics in section d (advance directives).

Group 3 would cover topics in section e (regulatory and financial issues).

Panel members chose work group assignments. Workgroup functions were outlined according to the following principles:

- Members would serve in work groups based on their expertise in certain areas, not just on their interest in a certain topic;
- Members would serve in only one work group because of logistics;
- Members would remember they are to contribute to the public good;
- Work groups would serve to advise the whole when reporting back to the Panel;
- Work groups would be created by the Panel and their work would be brought back to the Panel for approval;
- Work groups would elect a Chair/leader.

**Advisory Board.** In order to bring additional expertise to the discussion on end-of-life care, the Panel requested the development of an Advisory Board. Invitations were distributed and individuals representing diverse backgrounds and organizations were selected. Their names and addresses can be found in the Appendix 2.

**Meetings.** Organizational/working meetings were held in Tallahassee in July and August of 1998. From an initial list of possible geographic locations to hold public hearings, the Panel decided to receive public testimony in the following Florida cities: Orlando (September), Miami, Tamarac, and West Palm Beach (October), Sarasota, St. Petersburg, and Zephyrhills (November), and Jacksonville (December). The Panel met again on two occasions in January 1999 in Tallahassee. Subsequent to the Interim Report, the Panel met five times in Tampa (February) and Orlando (March, May, June, and July). Meeting schedules were posted and properly noticed in accordance with Florida Sunshine laws.

**Minutes.** Minutes were taken at the public hearings and at each of the Panel and Working Group meetings. (See Appendix 6)

## Issued Raised in Public Testimony.

Throughout the state, people raised a number of important concerns related to care provided at the end of life. The following list of items represents some of the problems as perceived by the public:

1. Concerns with advance directives:
  - Living Wills are not honored and wishes are not carried out at the end of life;
  - Documents are often confusing ;
  - Location and accessibility of documents when they are needed in a health emergency is problematic;
  - The lack of transportability of documents from different health care settings and across state lines is problematic;
  - The necessity of having a “terminal” illness diagnosis for a Do Not Resuscitate Order (DNRO) to be honored in certain settings and the necessity of having a “terminal” illness diagnosis for all other advance directives to be activated is problematic;
  - Circumstances under which advance directives are invoked are confusing;
  - People face difficulty in getting a terminal diagnosis even for very ill patients.
2. Concerns related to palliative care and pain management at end of life:
  - Concern over the lack of pain management and palliative care;
  - Concern over the lack of education for physicians and health care professionals in end of life care;
  - Misunderstanding and concern by physicians about the regulation of narcotics and subsequent hesitancy to prescribe pain medication;
  - Belief that pain should be considered as a 5<sup>th</sup> vital sign;
  - The need to include more hospice care in nursing homes.
3. Concerns with regulatory and financing barriers to care:
  - Concerns about conflicting regulations based on the location of end-of-life care;
  - Concerns regarding interpretation of federal and state eligibility criteria for Hospice resulting in denying access to hospice services;
  - Concerns regarding the lack of financing by Medicaid and Medicare for palliative care services;
  - Need to address the end-of-life care needs of the uninsured;
  - Misunderstanding of the OBRA requirement to provide the “highest practicable level of care” not being translated as excellent end-of-life care;
  - Confusion over the guardianship, health surrogacy and proxy regulations for institutionalized residents no longer competent to make health care decisions.
4. Uncertainty regarding procedures for making end-of-life care decisions for the “unbefriended”, and the need for better health care guardianship and surrogacy.

## Panel Goals and Concerns

Through the series of public meetings, discussions with providers, and the input of staff, administrators, and health care professionals who deal with these issues on a day-to-day basis, the Panel was able to identify a number of current problems with EOL care in Florida. The working groups developed proposals for addressing these problems. Proposals were discussed and framed as recommendations in open meetings of the full Panel. The problems addressed by the working groups included:

- ◆ Lack of communication among the various entities involved in delivering, regulating, and reviewing EOL care; lack of discussion on EOL care between physicians and patients and between patients and families.
- ◆ Difficulty in locating advance directives; consumer confusion regarding the appropriate procedures involved in defining the parameters of EOL care.
- ◆ Lack of standards in assessing/determining a person's capacity.
- ◆ Provider confusion regarding Florida Statute 765 and difficulty in the use of "terminal" diagnosis for invoking written advance directives, proxy or surrogate decision-makers; consumer confusion regarding the circumstances under which advance directives are invoked.
- ◆ Uncertainty as to procedures for making end-of-life care decisions for the "unbefriended"--incapacitated persons about whom little or nothing is known at the time.
- ◆ Physicians' concerns regarding regulations and medical board policies governing the prescription of controlled substances; concerns regarding medical examiners who are not familiar with the dosage levels necessary for pain management in patients with severe pain at the end of their lives.
- ◆ Lack of clear standards on EOL care and resulting inconsistencies in the quality of EOL care provided in the various health care settings where different requirements apply.
- ◆ Absence of formalized physician and nurse education requirements in the areas of DNR orders, advance directives, pain management and palliative care.
- ◆ Insufficient attention paid to multicultural differences in the way people view end-of-life-care decisions.

## Accomplishments of the 1999 Legislative Session

Based on the public meetings and extensive discussions, the panel submitted its Interim Report to the Legislature and the Governor on January 31<sup>st</sup>, 1999. After submitting its interim recommendations (see Appendix 3), the Panel was involved in shaping legislation to address its concerns. With the sponsorship of Senator Ron Klein and Representative Nancy Argenziano, bills for improving end-of-life care in Florida were introduced in both the House and the Senate. These efforts resulted in a widely supported bill, which passed the Senate on April 29<sup>th</sup> 1999 without opposition (37 yeas; 0 nays) and passed the House on April 30<sup>th</sup> 1999 without opposition (116 yeas; 0 nays). Governor Bush signed it into law on June 11<sup>th</sup>, 1999. The text of the bill is contained in Appendix 4; its legislative history is reported in Appendix 5.

### Senate Bill: CS/CS/SB2228

The Senate Bill CS/CS/SB2228 revised a number of statutory provisions relating to end-of-life care. In particular, portability of DNROs and recognition of advance directives were addressed. In addition, training and education of health care providers, provisions for anatomical gifts, and a continuing emphasis on the provision of quality end-of-life care were addressed. Included in the bill are provisions that:

- Authorize the Secretary of the Department of Health to develop and implement demonstration projects relating to recommendations of the Panel for the Study of End-of-Life Care, to report annually to the Legislature on project results, and to apply for grants and accept donations;
- Request the chancellor of the State University System to convene a workgroup to address the availability of end-of-life curricula for health care professionals in medical schools, schools of social work, and allied health disciplines;
- Encourage the use of pain as a “fifth vital sign;”
- Permit hospital emergency rooms, nursing homes, assisted living facilities, home health agencies, hospices, and adult family care homes to recognize DNR orders and provide liability protection when acting on the basis of such orders;
- Authorize health care providers to substitute a course on end-of-life care for the continuing education requirement for AIDS/HIV (if this course has been taken in a previous licensure cycle);
- Direct the Department of Health, in consultation with the Department of Elderly Affairs and the Agency for Health Care Administration, to develop a standardized do-not-resuscitate order (DNRO) system, and to permit the DOH to charge a fee to cover the cost of producing and distributing DNRO devices; also provides rule authority to implement this section;

- Expand provisions relating to transfer of a patient in instances of ethical conflict to apply to all treatment decisions not only decisions to forego life-prolonging procedures;
- Reduce the requirement for two physicians to determine the capacity of a principal when activating the authority of a health care surrogate, to a requirement that two physicians are necessary only when there is some question of whether the principal lacks capacity.
- Expand the term "advance directive" to include provisions relating to the authorization of anatomical gifts;
- Add "end-state condition" as an additional condition that will permit the withholding or withdrawal of life-prolonging procedures;
- Amend s. 765.107, F.S. to provide clarification that provisions of this chapter do not apply to persons who never had capacity to designate a surrogate or execute a living will;
- Create a procedure for discontinuing life-prolonging procedures for persons in a persistent vegetative state who have no advance directive and no one to act as their health care proxy;
- Prohibit health care facilities and providers from requiring a patient to execute an advance directive, or to use the facility or provider's forms; also directs that a patient's advance directive be made a part of the patient's medical record;
- Direct the Department of Elderly Affairs to convene a workgroup to develop model advance directive forms;
- Provide an effective date of October 1, 1999.

## Recommendations for the Florida Legislature

After submitting its Interim Report, the Panel continued to meet on a regular basis. The primary panel activities during this period were:

- ◆ Discussing the development of the bill and the legislative process involved in gaining passage;
- ◆ Reacting to proposed changes in the bill;
- ◆ Suggesting further revisions to the bill;
- ◆ Discussing the bill as passed;
- ◆ Reviewing panel goals;
- ◆ Revisiting interim recommendations in light of the new legislation;
- ◆ Formulating recommendations for the 2000 legislative session.

In reviewing its original goals and interim recommendations, panel members continued to organize their activities through the three workgroups. Improving education and training for providers and developing better tools and mechanisms for public education continued to be viewed as priority areas for progress. In addition, ensuring excellence in care at the end of life, coordinating care across various providers, regularizing procedures, developing forms that are recognized across providers, protecting patients' rights, and respecting cultural diversity require additional attention and policy formulation.

Based on an examination of what was accomplished in the 1999 legislation and a careful assessment of remaining impediments to providing quality end-of-life care in Florida, the Panel requests that the Florida Legislature consider and where possible implement these final recommendations, which are recorded in the remainder of this report. These recommendations were passed unanimously by the Panel, except where noted.

### Financial/Regulatory

1. The Legislature should create incentives for health and elder care providers and for publicly accessible media such as the press and public radio and television; these incentives should be designed to encourage public dialogue about advance directives and end-of-life care options. Incentives might take the form of citation in annual ratings for providers, private funding for public radio and television productions that reflect the multi-cultural diversity in our communities.
2. The Legislature should encourage the ongoing development of innovative end-of-life educational programs and standardized training for all health care providers.

3. The Legislature should encourage professional boards to accept standardized care training, including, but not limited to:
  - a.) pain management;
  - b.) advance directives, do-not-resuscitate orders, and living wills;
  - c.) hospice care;
  - d.) bereavement counseling; and
  - e.) clinical and ethical decision making.
4. The Legislature should recommend that professional organizations representing physicians, nurses, social workers, pharmacists, administrators of health care facilities, clergy and lawyers develop strategies to promote and provide incentives for participation in end-of-life training and that these professional organizations incorporate end-of-life education in their on-going educational activities.
5. The survey conducted by the chancellor of the state university system's work group on end-of-life curriculum should include a review of required health care texts and classroom instruction for inclusion of pain and palliative care instruction and clinical and ethical decision making in end-of-life care and make recommendations for basic end of life curriculum through the respective Boards of medicine, nursing, social work, pharmacy, and other health care disciplines.
6. Continuing education in end-of-life care may be substituted for any of the current mandatory continuing education requirements (not just HIV/AIDS), when these requirements have been met in previous cycles, for professions that include but are not limited to, physicians, nurses, social workers, pharmacists, administrators of health care facilities, clergy and lawyers.
7. In facilities and organizations licensed under Florida Chapter 400 and Chapter 395, the appropriate regulatory agency should recognize programs that demonstrate excellence in care at the end of life. Recognition might include end of life programs for inclusion in the Gold Seal Award for nursing homes.
8. The Legislature should remove regulatory barriers to accessing appropriate hospice service including consultation and early intervention programs for the enhancement of end-of-life care.

[Dr. Acker abstained]

9. Insurance plans, managed care plans, and Medicaid should include advance care planning as a reimbursement-coded service when provided by professionals trained in end of life and palliative care.



10. The Legislature should establish a working group made up of a representative from the Florida Legislature, staff representation from the House and Senate Appropriations committees, the Agency for Health Care Administration, the Department of Elderly Affairs, the Department of Health, and representatives from the respective provider associations. This working group should be charged with:
- a. Examining reimbursement methodologies for end-of-life care (such as consultative hospice service and a Medicaid case-mix reimbursement of palliative care);
  - b. Developing recommendations for incentives for appropriate end-of-life care;
  - c. Enabling all providers along the health-care continuum to participate in an excellent standard of end-of-life care.

### **Pain Management/ Palliative Care**

11. The Legislature should 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 achievement of the best quality of life for patients and their families.” [Cancer Pain Relief and Palliative Care. Technical Report Series 804. Geneva: World Health Organization, 1990]
12. All persons should have access to effective pain management and palliative care services. We recommend that the legislature amend the current Patient Bill of Rights to include specific reference to access to pain and palliative care.
13. Providing pain management to achieve acceptable comfort for people at the end of life, when provided in full compliance with the Chapter 30 “Intractable Pain Statute,” should be construed as meeting the standard of medical care. Nothing in this recommendation should be taken to promote or condone physician-assisted suicide or euthanasia.
14. The Florida legislature should adopt language to promote the following recommendations:
- Professional education:
- a. Encourage medical, nursing, social work, and pharmaceutical schools throughout the state to review and implement curricula designed to train providers in principles of pain management and palliative care;
  - b. Encourage development of materials and courses designed to educate practicing health-care professionals on appropriate standards on pain management and palliative care;
  - c. Promote specialist training programs (palliative care fellowship program) for physicians in each of Florida’s medical school;

- d. Promote specialist training for nurses, nurse practitioners, pharmacists, social workers to create a cadre of palliative care specialists;
- e. Promote increased and earlier referral to hospice programs for appropriate patients;
- f. Establish programs on end-of-life care at one or more centers to serve as centers of research and policy analysis on end-of-life care in the state.

Public Education:

- a. Create a statewide education campaign to improve understanding of palliative care, to enhance access to hospice and palliative care services and to promote understanding of the need for advance care planing and advance directives;
  - b. Create culturally sensitive education programs to improve end-of-life care in minority communities.
15. Where appropriate, the Agency for Health Care Administration, the Department of Elderly Affairs, and the Department of Health should be directed to develop or adopt reasonable approaches to ensure effectiveness of pain and palliative care strategies. Such strategies may include but not limited to:
- a. Providing information regarding the options for care and support that exists within the local community;
  - b. Providing an opportunity to participate in advance care planning and discussions of choices and decisions with appropriate providers;
  - c. Developing protocols for excellence in pain management and the management of other distressing symptoms at the end of life;
  - d. Reviewing/redesigning organizational policies and procedures that may either pose barriers to effective palliative care or promote effective palliative care;
  - e. Developing strategies to monitor and improve the effectiveness of pain management and the organizational standards used to evaluate end-of-life care;
  - g. Developing interdisciplinary approaches to meet the social, emotional, spiritual, and bereavement concerns of people at the end-of-life and their families.
16. Health care facilities, other organizations, and providers caring for people at the end of life should develop strategies to provide access to palliative care. Standards for pain management, management of other distressing clinical symptoms at the end of life, advance care planning, and systems to attend to emotional and spiritual needs should be in place or available in all settings which care for seriously ill patients.
17. The Panel recognizes that too many Floridians are dying without adequate pain management. To provide appropriate pain relief to patients, particularly patients at the end of life, we recommend that health-care boards adopt rules concerning guidelines for pain management. We also recommend that these boards develop and promote educational programs to disseminate information regarding these rules and practices.

18. The Florida Legislature should designate specific funding of studies to determine the clinical needs, costs, and services available to Floridians dying at home, hospice, hospital, assisted living centers, nursing homes, and those without health-care insurance.

## Advance Directives

19. 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. This right extends to competent and incompetent persons alike. We propose the removal of such language as "terminal condition" and "end stage condition" which may represent impediments to the implementation of patients' choices. It is our recommendation that the Florida Legislature remove from chapter 765 all language which stands in the way of fulfilling patients' rights.<sup>19</sup>

[Dr. Brooks abstained]

20. The legislature (as well as private sources) should encourage and, where appropriate, fund efforts by state agencies, professional societies, universities, community colleges, and civic organizations to educate consumers, the general public, and health care providers about patients' advanced care planning. This education should include how to implement the patient's unique wishes with sensitivity to the patient's cultural heritage.
21. The legislature should continue to encourage creation of a standardized and portable do-not-resuscitate (DNR) form that can be used in all patient settings. They should also enact procedures necessary to facilitate the effective use of this form.<sup>20</sup>
22. The phrase "mentally and physically" is confusing and unnecessary. We therefore recommend that the phrase "mentally and physically" be deleted from Chapter 765.
23. We recommend that only one physician be required to determine whether the medical condition or limitation referred to in an advance directive exists.

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<sup>19</sup> Please see pages 173-178 of the minutes for the discussion related to this issue. Jim Towey, who was not present at the meeting, sent a representative to register his disagreement with this recommendation.

<sup>20</sup> Legislation passed in 1999 (CS/CS/SB2228) directed the Department of Health to develop a standardized do-not-resuscitate form that would be recognized in multiple health care settings and authorized the appropriate liability protection for health care providers acting on the basis of such orders. It was unclear to the Panel whether non-emergency-room hospital settings were included in this directive; therefore, the Panel thought it advisable to request that the Legislature revisit this issue.

## Other Outcomes Related to the Panel's Activities

**Grant Applications.** A variety of requests for project funding have been submitted to federal agencies (e.g., National Institute of Health) and private foundations (e.g., The Robert Wood Johnson Foundation). These projects represent collaborative arrangements among members of the panel and their respective organizations and are designed to implement and evaluate programs involved in delivering end-of-life care in Florida

**Development of Specialized Hospice Program.** The Hospice of the Florida Suncoast and Menorah Manor are collaborating in the development of *The Toby Weinman Jewish Hospice Program*, which will provide hospice care to members of the Jewish community. Mary Labyak, President and Executive Director of the Hospice of the Florida Suncoast and Marshall Seiden, CEO of Menorah Manor, serve on the Panel. This initiative is an example of the kind of interagency collaboration encouraged by the Panel.

**New University Program.** The Pepper Institute on Aging and Public Policy at Florida State University is establishing a new program to address end-of-life issues. This program includes basic research, education, and public service components. Information about this developing program will be available at [www.pepperinstitute.org](http://www.pepperinstitute.org).

**New Collaborations.** Florida Hospices and Palliative Care, Inc., has strengthened collaborative projects across the state for public education and public engagement and has submitted grant applications for same.

**Development of "Best Practices in End-of-Life Care for Nursing Homes and Assisted Living Facilities."** The Florida Health Care Association is developing a best practices education program for a late fall implementation. Dr. Howard Tuch, National Palliative Care Director for Genesis Elder Care, and LuMarie Polivka-West, FHCA Policy Director, are working with the Agency for Health Care Administration to provide training on quality of remaining life, pain and symptom control, spiritual and emotional support of residents and families.

**Information Dissemination.** Cathy Emmett, Samira Beckwith and Mary Labyak presented information about the Panel's work and progress in addressing end-of-life issues at the *National Hospice Leadership Meeting* in Washington, DC;

Ken Goodman, Jane E. Hendricks, Cathy Emmett and Dr. Bob Brooks made a presentation on end-of-life issues at the Florida Bioethics Network meeting;

Marshall Seiden, Kate Callahan, and Cathy Emmett presented on end-of-life issues at the *Florida Association of Homes for the Aging* meeting.

Cathy Emmett has written two articles describing the work of the Panel of the *Florida Nurse*

Members of the Panel, in conjunction with Melissa A. Hardy, will present a symposium titled: **Innovations in Florida's Approach to End-of-Life Care** at the 49<sup>th</sup> Annual Meeting of the *American Society on Aging*.

Information collected during the Panel's public hearings will be included in a presentation on "Living and Dying Well in Nursing Homes," made by Howard Tuch, M.D., LuMarie Polivka-West, Rosalie Kane, DSW, University of Minnesota, and Bob Kane, M.D., University of Minnesota at the 1999 American Health Care Association's 50<sup>th</sup> Annual Conference.

Appendix 1  
CS/CS/HB3387



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A bill to be entitled  
An act relating to health care; amending s.  
430.502, F.S.; establishing additional memory  
disorder clinics; revising authority of the  
Department of Elderly Affairs with respect to  
contracts for specialized model day care  
programs at such clinics; amending s. 430.707,  
F.S.; authorizing the department to contract  
for certain services; exempting certain  
providers from the provisions of ch. 641, F.S.;  
creating the Panel for the Study of End-of-Life  
Care; providing for membership and duties;  
requiring a report; providing for future  
repeal; providing an effective date.

Be It Enacted by the Legislature of the State of Florida:

Section 1. Subsections (1) and (4) of section 430.502,  
Florida Statutes, are amended to read:

430.502 Alzheimer's disease; memory disorder clinics  
and day care and respite care programs. --

(1) There is established:

(a) A memory disorder clinic at each of the three  
medical schools in this state;

(b) A memory disorder clinic at a major private  
nonprofit research-oriented teaching hospital, and may fund a  
memory disorder clinic at any of the other affiliated teaching  
hospitals;

(c) A memory disorder clinic at the Mayo Clinic in  
Jacksonville;



1 (d) A memory disorder clinic at the West Florida  
2 Regional Medical Center;

3 (e) The East Central Florida Memory Disorder Clinic at  
4 the Joint Center for Advanced Therapeutics and Biomedical  
5 Research of the Florida Institute of Technology and Holmes  
6 Regional Medical Center, Inc.;

7 (f) A memory disorder clinic at the Orlando Regional  
8 Healthcare System, Inc.; and

9 (g) A memory disorder center located in a public  
10 hospital that is operated by an independent special hospital  
11 taxing district that governs multiple hospitals and is located  
12 in a county with a population greater than 800,000 persons;

13 (h) A memory disorder clinic at St. Mary's Medical  
14 Center in Palm Beach County; and

15 (i) A memory disorder clinic at Tallahassee Memorial  
16 Regional Medical Center,

17  
18 for the purpose of conducting research and training in a  
19 diagnostic and therapeutic setting for persons suffering from  
20 Alzheimer's disease and related memory disorders. However,  
21 memory disorder clinics funded as of June 30, 1995, shall not  
22 receive decreased funding due solely to subsequent additions  
23 of memory disorder clinics in this subsection.

24 (4) Pursuant to the provisions of s. 287.057, the  
25 Department of Elderly Affairs may contract for the  
26 Provision of specialized model day care programs in  
27 conjunction with the memory disorder clinics. The  
28 purpose of each model day care program must be to provide  
29 service delivery to persons suffering from Alzheimer's disease  
30 or a related memory disorder and training for health care and  
31

1 social service personnel in the care of persons having  
2 Alzheimer's disease or related memory disorders.

3 Section 2. Section 430.707, Florida Statutes, is  
4 Amended to read:

5 430.707 Contracts.--

6 (1) The department, in consultation with the agency,  
7 shall select and contract with managed care organizations to  
8 provide long-term care within community diversion pilot  
9 project areas.

10 (2) The department, in consultation with the agency,  
11 may contract with entities which have submitted an application  
12 as a community nursing home diversion project as of July 1,  
13 1998, to provide benefits pursuant to the "Program of  
14 All-inclusive Care for the Elderly" as established in Pub. L.  
15 No. 105-33. For the purposes of this community nursing home  
16 diversion project, such entities shall be exempt from the  
17 requirements of chapter 641, if the entity is a private,  
18 nonprofit, superior-rated nursing home with at least 50  
19 percent of its residents eligible for Medicaid.

20 Section 3. (1) There is hereby created the Panel for  
21 the Study of End-of-Life Care, which shall be located in the  
22 Pepper Institute on Aging and Public Policy at Florida State  
23 University, to study the issues related to care provided to  
24 persons at the end of life.

25 (2) The panel shall be composed of 22 persons, as  
26 follows:

27 (a) Two persons who are representatives of hospice  
28 organizations, and one consumer, to be appointed by the  
29 Florida Hospice Association.

30 (b) Three persons who are representatives of nursing  
31 homes and assisted living facilities and who have the

1 experience necessary to participate in the work of the panel.  
2 Two of these persons shall be appointed by the Florida Health  
3 Care Association and one by the Florida Association of Homes  
4 for the Aging.

5 (c) Three persons who are representatives of hospitals  
6 and who have the expertise necessary to participate in the  
7 work of the panel, one each to be appointed by the Florida  
8 Hospital Association, the Florida League of Health Systems,  
9 and the Association of Community Hospitals and Health Systems  
10 of Florida, Inc.

11 (d) One member each to be appointed by the Florida  
12 Medical Association, the Board of Medicine, the Board of  
13 Osteopathic Medicine, The Florida Bar, and the Florida Nurses  
14 Association, who have the expertise necessary to participate  
15 in the work of the panel.

16 (e) One member of the Florida Senate appointed by the  
17 President of the Senate and one member of the Florida House of  
18 Representatives appointed by the Speaker of the House.

19 (f) One representative of the Aging with Dignity  
20 Commission.

21 (g) Two representatives appointed by the Pepper  
22 Institute, including a member of the clergy, with the  
23 expertise necessary to participate in the work of the panel.

24 (h) One representative from the Health Quality  
25 Assurance Division of the Agency for Health Care  
26 Administration with expertise in the regulation of long-term  
27 care facilities.

28 (i) The Secretary of Elder Affairs, and one consumer  
29 representative appointed by the secretary.

30 (3) The members of the panel shall be appointed by  
31 July 1, 1998, and shall hold an initial meeting of the panel

1 by August 1, 1998. All expenses of the panel, including travel  
2 and per diem expenses, shall be paid by the entities  
3 appointing members pursuant to subsection (2), in proportion  
4 to the number of members appointed by them. The Pepper  
5 Institute shall provide such staff support for the panel as is  
6 requested by the panel. The panel shall hold such hearings as  
7 it deems appropriate to receive public testimony as to its  
8 proposed recommendations and findings. Notice of all meetings  
9 of the panel and of its public hearings shall be provided in  
10 the Florida Administrative Weekly.

11 (4) The panel is directed to study issues related to  
12 the care provided to persons at the end of life. Issues  
13 considered by the panel shall include:

14 (a) Methods to ensure that pain management is a goal  
15 in each health care setting.

16 (b) The identification of barriers that hinder health  
17 care professionals from providing satisfactory pain management  
18 and palliative care.

19 (c) Whether mandatory education in pain management and  
20 palliative care should be required as a condition for  
21 licensure or relicensure of health care professionals. The  
22 Pepper Institute shall consult with health care professional  
23 licensing boards in completing this phase of the study.

24 (d) The current use of advance directives, to  
25 determine whether changes are necessary to ensure that, once  
26 prepared, advance directives will be honored in any health  
27 care setting.

28 (e) The regulatory and financial incentives that  
29 influence the site or setting of care and of care providers.

30 (5) The panel shall submit an interim report by  
31 January 31, 1999, and a final report by August 1, 1999, to the

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Governor, the President of the Senate, and the Speaker of the House of Representatives.

(6) This section shall stand repealed effective August 1, 1999.

Section 4. This act shall take effect July 1 of the Year in which enacted.

## Appendix 2

### Panel, Alternate, and Advisory Board Members



**Panel Member:****Alternate:**

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## ***Biographical Sketches.***

### **Rev. Celillon Alteme**

#### ***Tampa General Healthcare***

Reverend Alteme is a Southern Baptist ordained minister who was born and raised in Haiti. He holds a Masters of Divinity and a Masters of Christian Education. A member of the Association for Clinical Pastoral Education, Reverend Alteme is a certified supervisor of Clinical Pastoral Education at Tampa General Healthcare where he also serves on the hospital Ethics Committee. Member beginning in January.

### **Samira K. Beckwith**

#### ***President and CEO, Hope Hospice and Palliative Care***

Representing Florida Hospices and Palliative Care, Inc., Samira K. Beckwith has served as President and CEO of Hope Hospice since 1991 and is currently President of Florida Hospices, Inc., the state hospice association. She has played a leadership role in the hospice movement at the local, state, and national level for more than 20 years. She is the former Chairperson of the National Hospice Organization and held numerous leadership positions on its Board of Directors. Member.

### **Dr. Bob Brooks, MD**

#### ***Secretary, Florida Department of Health and Former Member, District 35, Florida House of Representatives***

Dr. Brooks, the newly appointed Secretary of the Department of Health, served for four years in the Florida House of Representatives and previously chaired the Legislative Committee on Elder Affairs and Long Term Care. He has been a practicing physician specializing in infectious diseases since 1984. Member/Alternate.

### **Pete J. Buigas**

#### ***Director of Health Quality Assurance, Agency for Health Care Administration***

Mr. Buigas currently holds the position of Deputy Director for Health Quality Assurance and Manage Care. Responsible for facility licensing, manage care regulation, Community Health Purchasing Alliances (CHPA), administration of certificate of need program and practitioner complaint investigations for the State of Florida. Member beginning in January.

### **Meta Calder, J.D.,**

#### ***Assisted Living, Hospice, and End-of-Life Issues, Department of Elderly Affairs***

Ms. Calder was a staff attorney for the Health care Committee, Florida House of Representatives, and was responsible for drafting legislation relating to advance directives from 1991 until 1997. She also provided technical assistance in drafting the Panel's 1999 legislation. Alternate.

### **Dr. Marie E. Cowart**

#### ***Professor of Urban and Regional Planning, Florida State University***

Dr. Cowart has long been active in the field of aging and is a recognized expert in public health, applied gerontology, and long-term care. She served as Director of the Pepper Institute on Aging and Public Policy from 1985 to 1992 and is a past President of the Florida Nurses Association. She currently teaches in the Health Systems and Aging

Policy Specialization, a masters and doctoral program at Florida State University.  
Member.

**Cathy Emmett**

***Florida Nurses Association***

Ms. Emmett has been a nurse for 17 years and has worked in a variety of settings. She has served on Bioethics Committees in Hospitals and LTC Facilities for the past 15 years. She is a Board member of the Florida Bioethics Network and is the nursing representative to the Ethics Committee of the American Geriatrics Society. Cathy has a BSN and an MSN in nursing and is a certified Geriatric Nurse Practitioner. Member.

**Joan Fulbright**

***Director of Senior Services, Orlando  
Regional Healthcare System***

Ms. Fulbright has been with the Orlando Regional Healthcare system for 12 years, and was a founding member of the Orlando Regional Medical Center's Ethics Committee. Her current responsibilities include the development and management of all community-based social services for elders. She represents the Association of Community Hospitals and Health Systems on this panel. Member.

**Stan Godleski**

***Consumer Advocate***

Stan Godleski was President of a 3,000 member nonprofit funeral consumer association. He currently serves as Vice Chair of the Board of Trustees of Hospice of Southeast Florida and as Vice Chair of the Citizens' Advisory Committee of Sarasota Memorial Hospital. He has held a variety of positions with AARP, including state director for Florida and chapter president, and is active and a leader in many aspects of his community. He is a retired public school teacher and administrator. Member.

**Jack Gordon**

***Hospice Foundation of America***

Since 1990 Mr. Gordon has been President of the Hospice Foundation of America. He previously directed the Institute of Public Policy and Citizenship Studies at Florida International University and served for six terms in the Florida Senate (1972-1992). Member.

**Dr. Gema G. Hernandez**

***Secretary, Department of Elder Affairs***

*Dr. Hernandez* was appointed the Secretary of the Florida Department of Elderly Affairs early in 1999. Since 1989, she has been a full professor on the faculty of the School of Business and Entrepreneurship at Nova Southeastern University. Dr. Hernandez also served as a management consultant to numerous organizations, including Lifeline Systems, Inc., Neighborly Senior Services, Inc., Detroit Area Agency on Aging, and Senior Services of Albany, New York. Member beginning in January.

**Marshall Kelley**

***Director of Health Quality Assurance,  
Agency for Health Care Administration***

Mr. Kelley directs the division which is responsible for licensing, surveying, and certifying over 18,000 health care facilities. He has 29 years of experience in health, education, and social services programs in Florida, including serving as Medicaid Director and other professional positions in the Florida Department of Health and Rehabilitative Services. Member through December.



**The Honorable Ron Klein*****Florida Senate***

State Senator Ron Klein is currently serving his second term in the Florida Senate. He was elected to the Senate in 1996 after serving four years in the Florida House of Representatives. His keen interest and past experience with health care issues, including long term care and gerontology, prompted the Senate President to appoint him as the Senate representative to the Panel for the Study of End-of-Life Care. Member.

**K. Joe Krieger,*****Executive Director, Florida Developmental Disabilities Council, Inc.***

Joe Krieger is the First President and Founder of The Consortium of Developmental Disabilities Councils, a national advocacy organization. He is credited with turning a small state agency into a private, nonprofit organization (the only one of its kind in the nation). Alternate (FHCA)

**Mary Labyak*****Executive Director and CEO, Hospice of the Florida Suncoast***

Representing Florida Hospices and Palliative Care, Inc., Ms. Labyak has worked for the rights of the terminally ill for nearly 20 years. She has served as Executive Director and President of The Hospice of Florida Suncoast since 1983. The Hospice of the Florida Suncoast is the largest community-based Hospice in the United States. She is past chairperson of the National Hospice Organization and Long term Chair of Public Policy for Florida Hospices and Palliative Care, Inc. She has received numerous awards recognizing her work in the fight against AIDS and her humanitarian efforts on behalf of dying people. Member.

**E. Bentley Lipscomb*****Former Secretary, Department of Elder Affairs***

Mr. Lipscomb served as Secretary of the State of Florida Department of Elder Affairs since 1991 and has been active in numerous arenas that affect the lives of older people in Florida. He served in Washington as the staff director of the U.S. Senate Special Committee on Aging and as deputy staff director of the Senate Budget Committee at a time when elder-related programs constituted a third of federal spending. Member through December.

**Belita Moreton*****Florida League of Health Systems***

Ms. Moreton is vice-president, attorney, and lobbyist for the Florida League of Health Systems, which is the trade association representing investor-owned hospitals and facilities in Florida. She graduated from the Florida State University College of Law in 1987 and is also a Registered Nurse. Member.

**Dr. Robert Panzer, DO*****Florida Board of Osteopathic Medicine***

Dr. Panzer is past-president of the Florida Osteopathic Medical Association. He was appointed by Governor Chiles to the Board of Osteopathic Medicine in 1996. From 1975 to the present, he has been in private practice at Colours Medicine in Ocala, Florida. Member.

**LuMarie Polivka-West*****Senior Director of Policy and Quality Assurance, Florida Health Care Association***

Ms. Polivka-West has over 20 years of health management experience as the former Licensure and Certification Director and Medicaid Program Chief. She is the President of the Board of Directors of the Alzheimer's Resource Center in Tallahassee and the Chair of the Aging Subcommittee of the Clearinghouse for Human Services, a state-wide advocacy organization. Member.

**Kenneth S. Rubin**

*The Florida Bar*

Mr. Rubin is an attorney in Ft. Lauderdale where he has been practicing law since 1977. He specializes in Elder Law and is nationally certified by the National Elder Law Foundation (charter certification). Mr. Rubin is currently Chair-elect of the Elder Law Section of the Florida Bar and Vice-President of the Area Wide Council on Agency of Broward County. Mr. Rubin further serves as Chairman of the Housing Committee for Hillmont Gardens, Broward County's HUD housing for the elderly poor. Mr. Rubin served as a founding Director of Alzheimer Association of Broward County and as a Director of the Combined Health Appeal of Broward. Member.

**Dr. Leo Sandon<sup>3</sup>**

*Professor of Religion, Florida State University*

Dr. Sandon's academic interests include ethical issues of an aging society. An ordained minister, he was founding director of the Institute for Social Policy Studies and former Chair of Religion. He writes a regular column, "Religion in America" for the *Tallahassee Democrat*. Member through December.

**Marshall Seiden**

*CEO, Menorah Manor Inc.*

Mr. Seiden is the Chief Executive Officer and Executive Director of Menorah Manor and the Menorah Manor Foundation, a major not-for-profit geriatric center sponsored by the Jewish community of Florida's west coast. During his 29 year career he has held executive positions in several long term care and hospital settings and is currently Nursing Home Vice President of the Florida Association of Homes for the Aging. Member.

**Dr. Alvin E. Smith, MD**

*Regional Oncology Center*

Dr. Smith is the Medical Director of the H.D. Kerman Regional Oncology Center. He has served as President of the Florida Medical Association and Chair of the Florida State Commission on Pain. He is a lay member of the Florida Bar Association and a member of the Florida Commission on Aging with Dignity, as well as the Cancer Control and Research Advisory Council. Member.

**Jim Towey**

*Commission on Aging with Dignity*

Currently the President of the Commission on Aging with Dignity, Mr. Towey also founded this organization in 1996. He was previously appointed head of the Department of Health and Rehabilitative Services (HRS) in Miami, and he then served as the Secretary of the Florida Department of Health and Rehabilitative Services, 1993-1995. Member.

**Dr. Howard Tuch, MD**

*Director of Palliative Care Services,  
Genesis ElderCare*

Dr. Tuch is a board-certified internist and geriatrician. His current position is that of Director of Palliative Care Services for Genesis ElderCare, a geriatric health care company with over 350 centers nationwide. He is also director of the Palliative Care

Program at Egret Cove nursing center in St. Petersburg. His clinical practice is limited to those in the final stages of terminal illness. Member.

**Dr. Susan V. White**

*Vice President/Quality Management,  
Florida Hospital Association*

Dr. White has over 20 years of experience in the health care field in administrative, managerial, and clinical roles. She is also on the faculty at the University of Phoenix-Florida Campus. Member.

**Dr. Gary Winchester, MD**

*Florida Board of Medicine*

Dr. Winchester has served on numerous state and local committees, including chair of the State Legislative Committee, President of the Tallahassee Physicians Association and the Quality Assurance Committee of Healthplan Southeast. He also served as chair of the Tallahassee Memorial Regional Medical Center Medical Executive Committee. Member.

## Appendix 3

### Interim Report Recommendations



**Panel's Interim Recommendations**  
**January 31<sup>st</sup> 1999**

**Pain Management/Palliative Care Working Group**

**General goals--** The workgroup's focus is to improve and enhance pain management and care. It was the consensus of the workgroup to focus on educational efforts for the interim report.

The workgroup identified the following goals:

- To provide effective education for physicians and health care practitioners;
- To develop a directory of resources and a Helpline for last minute physician references regarding medications;
- To provide incentives for education instead of mandating it;
- To educate the public directly to increase their awareness of pain management so that they can ask questions and secure better care;
- To conduct research to determine the availability of good palliative care, given that information suggests that many homebound patients and residents of nursing homes are not receiving adequate pain management;
- To address the importance of access to medications, and the difficulty of getting narcotics at night from a pharmacy;
- To promote care that will prevent pain in addition to providing care in reaction to pain;
- To achieve widespread recognition that it is unacceptable for a patient to remain in pain.

**Recommendations:**

1. All persons should have access to effective pain management and palliative care services. Dying has become a difficult grace within our modern and technologically driven health care system. The Florida legislature can promote meaningful change in the delivery of medical care at the end of life.
2. Adopt the World Health Organization's definition of Palliative Care. Palliative care is defined according to the World Health Organization 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."
3. Health care facilities, other organizations, and providers caring for people at the end of life should develop strategies to provide access to palliative care. Standards for pain management, management of other distressing clinical symptoms at the end-of-life, advance care planning, and systems to attend to emotional and spiritual needs should be in place or available in all settings which care for seriously ill patients.
4. The Agency for Health Care Administration and the Department of Elder Affairs should be directed to develop or adopt reasonable standards to monitor the implementation and effectiveness of pain and palliative care strategies.

Such standards may include:

- a. Providing information regarding the options for care and support that exists within the local community;
  - b. Providing the opportunity to participate in advance care planning and discussions of choices and decisions with appropriate providers;
  - c. Providing excellence in pain management and the management of other distressing symptoms at the end of life;
  - d. Reviewing/redesigning organizational (i.e., health care facilities') policies and procedures that may pose barriers to rather than promote effective palliative care;
  - e. Instituting strategies to monitor and improve the effectiveness of pain management and organizational standards for end-of-life care;
  - f. Establishing interdisciplinary approaches to meet the social, emotional, spiritual and bereavement concerns of people at the end-of-life and their families.
5. Pain management to achieve acceptable comfort for people at the end of life, when provided in full compliance with Section 458.326 of the Medical Practice Act (the "Intractable Pain Statute"), should be construed as meeting the standard of medical care. Nothing in this recommendation should be taken to promote or condone physician assisted suicide or euthanasia.

[5 dissenting votes<sup>1</sup>]

6. The Panel recognizes that too many Floridians are dying without adequate pain management. To provide appropriate pain relief to patients, particularly patients at the end-of-life, we recommend that health-care boards adopt rules concerning guidelines for pain management. We also recommend that these boards develop and promote educational programs to disseminate information regarding these rules and practices.
7. The Florida legislature should adopt language to promote the following recommendations:

**Professional education.**

- a. encourage medical, nursing, social work, and pharmaceutical schools throughout the state to review and implement curricula designed to train providers in the principles of pain management and palliative care;
- b. encourage development of materials and courses designed to educate practicing health-care professionals on appropriate standards of pain management and palliative care;
- c. promote specialist training programs (palliative care fellowship programs) for physicians in each of Florida's medical schools;
- d. promote specialist training programs for nurses, nurse practitioners, pharmacists, and social workers to create a cadre of palliative care specialists;
- e. promote increased and earlier referral to hospice programs for appropriate patients;

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<sup>1</sup> Dissenters wanted the recommendation to read "Aggressive pain management to achieve acceptable comfort for people at the end of life . . ."

- f. establish a program on end-of-life care at the Pepper Institute on Aging and Public Policy at FSU to serve as a center of research and policy analysis on end-of-life care in the state.

**Public education**

- a. create a state-wide education campaign to improve understanding of palliative care, enhance access to Hospice and palliative care services and to promote understanding of the need for advance care planning and advance directives;
  - b. create culturally sensitive education programs to improve end-of-life care in minority communities.
- 
8. The Florida Legislature should designate specific funding for studies to determine the clinical needs, costs and services available to Floridians dying at home, in Hospice, in the hospital, in assisted living facilities, in nursing homes, and to those without health-care insurance.



## Advance Directives Working Group

**General goals:** The group's mission is to examine the current use of advance directives and to determine whether changes are necessary to ensure that, once prepared, advance directives will be honored in any health care setting.

Emphasis was placed on the importance of self-determination through the use of advance directives. Advance directives include: living wills, health care surrogate forms and do not resuscitate orders (DNROs). Some of the difficulties in having these documents honored include the following:

- A terminal illness is required for advance directives to be employed and for wishes to be honored.
- In a hospital setting one need not be "terminally ill" to have a DNRO. However, when a patient is "Pre-hospital" the person must be terminally ill to have a DNRO. This difference leads to confusion about the use of DNROs.
- Patients may have difficulty getting support in the hospital for DNROs and compliance with advance directives.
- Lack of agreement and confusion exists among physicians, consumers and their families about when the advance directive should be employed.
- Professional disagreements can occur among physicians in determining when a patient is terminally ill.
- Lack of agreement exists among physicians, patients and their families as to appropriate designation of terminal illness as stipulated in the statute.
- There are multiple advance directive and DNRO forms for different health care settings without continuous access to or portability of the forms.
- Lack of communication exists about advance directives and end-of-life care treatment among physicians and patients and their family members.
- Consumers and professionals do not understand the law (Florida Statute 765) and the responsibilities of all concerned persons regarding health care surrogacy.

Other items raised for discussion include:

- F.S. 765 and 401 - How do they fit? What was their origin? Why must two physicians agree that a person's condition is terminal?
- Emergency Medical Services technicians (EMTs) are concerned that the public does not understand the difference between living wills and DNROs.
- There is a need for simplification of forms and processes.
- Immunity from liability or protection from prosecution is needed for EMTs and other caregivers when honoring advance directives.
- There is little or no community education about advance directives;
- Multicultural environments make the situation even more complex.
- Questions exist as to the constitutionality of the current restriction in Florida law that advance directives can only be implemented when a patient is "terminally ill."
- Are the procedures for determining "capacity" appropriate for all health care settings?

The workgroup decided to focus on the following areas:

- Removal of barriers in F.S. 765 and 401 that make it difficult to honor advance directives;
- The definition of "terminal" and the associated need for two physicians to attest to the condition as a potential conflict with right of self-determination;
- The need to address self-determination and the valid refusal of treatment as they are not sufficiently incorporated into the current statute.
- When appropriate, EMS workers and other caregivers need to be protected from liability when honoring DNROs and advance directives.

***Recommendations:***

1. Recommend that the Florida Legislature remove from F.S. 765 the requirement that a person be “terminally ill” before life-prolonging procedures can be withheld or withdrawn.  

[1 dissenting vote<sup>2</sup>]
2. Recommend that the Legislature create a standardized and portable DNRO form that can be used in all patient settings. Create policy and procedures to implement the effective use of this form.
3. Recommend that the Legislature provide for “demonstration projects” by local communities in conjunction with the Department of Health as to mechanisms for implementation of pre-hospital DNROs.
4. If a legally executed advance directive has been executed, we recommend the requirement of the assessment and evaluation of one physician as to the patient’s capacity. In the absence of a legally executed advance directives, we recommend two (2) physicians or one physician and one of the following professional licensed health care providers: ARNP (advanced registered nurse practitioner), PA (physician’s assistant), Psychologist, LCSW (licensed clinical social worker) determine the patient’s capacity.

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<sup>2</sup> The dissenter agreed that the current definition of terminal illness contained in the statute is seriously flawed, but would prefer rewriting the definition—perhaps expanding it to include some chronic conditions--and retaining the term in the statute.

## **Financial and Regulatory Working Group**

**General Goals:** Members of the work group decided to focus on: defining the continuum of end-of-life care; identifying relevant actors (facilities, health care providers, etc.); identifying gaps and the legal/regulatory barriers for each domain (i.e. different forms for advance directives, financing inequities such as the lack of case-mix for Hospice); and identifying areas in which to make policy recommendations. Areas that the group identified as concerns include:

- the education of doctors, other health care practitioners and the public about end of life care;
- the issue of how to change the training of physicians and health care providers; whether or not to make education in end-of-life care mandatory, and whether this would increase participation; how to ensure that people attend training and take learning the material seriously;
- the need for different levels of training depending on type of physician or health care professional;
- removal of barriers to referrals and timely referrals to Hospice;
- improving access to hospice services;
- addressing the gap in funding between state law (last year of life) and Medicaid and Medicare (last 6 months), and the need for multiple levels of reimbursement;
- the need for demonstration projects to try alternative funding and eligibility criteria;
- concern over placement decisions and the transfer of patients;
- the need to evaluate and expand ongoing studies of patient outcomes to develop a measure of the quality of end-of-life care and a 'good' death (dying where they wanted to and with minimal pain);
- the need for a commitment to the discussion of end-of-life care at the beginning of the treatment process (during admissions, for example).

### ***Recommendations:***

The Panel recognizes a need for a societal change in understanding and supporting good end-of-life care. Treatment patterns of physicians, decisions by family members and the terminally ill individual, and the level of understanding in the larger community will be effected by an improved understanding of what constitutes good end-of-life care and the opportunity to experience a quality life until the very end. With that outcome in mind, the Panel unanimously endorses the following goals:

- 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.
- 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.
- the right of all persons, regardless of insurance status, to be provided access to good end-of-life care.

We recognize the vital importance of good end-of-life education for all people practicing in health care, human services and related areas and recommend that the following recommendations be adopted.

1. that continuing education in end-of-life care may be substituted for any of the current mandatory continuing education requirements (when these requirements have been met in previous cycles) for professions that include but are not limited to, physicians, nurses, social workers, pharmacists, administrators of health care facilities, clergy and lawyers.
2. that the Legislature encourage the ongoing development of innovative end-of-life educational programs for all health care providers.
3. that the Legislature recommend that professional organizations representing the aforementioned groups develop strategies to promote and provide incentives for participation in end-of-life training and that these professional organizations incorporate end-of-life education in their on-going organizational activities.
4. that the Legislature authorize the creation of a work group comprised of but not limited to a representative from the Board of Medicine, the Board of Osteopathic Medicine, the Board of Nursing, the Board of Pharmacy, the Board of Nursing Home Administrators, one School of Medicine, one School of Social Work, and Chairs of the four (4) Florida medical schools' curriculum committees, to review available curricula on end-of-life care and make recommendations through the respective Boards for curriculum materials to be incorporated into the basic curriculum of each school of medicine, nursing, social work, pharmacy, and other health related disciplines.
5. that the Legislature create incentives for health and elder care providers and for publicly accessible media such as the press and public radio and television designed to encourage public dialogue about advance directives and end-of-life care options. Incentives might take the form of citation in annual ratings for providers, and private funding for public radio and television productions that reflect the multicultural diversity in our communities.
6. that the Legislature institute a legislative proposal that encourages excellence in end-of-life care. Criteria of excellence should include but not be limited to: 1) a mechanism for effective conflict resolution regarding end-of-life decisions (e.g. an active ethics committee); 2) a facility-based palliative care program ; 3) and/or a formal affiliation with a hospice organization. Such conditions should define eligibility for awards recognizing excellence in health care facilities (e.g. a Gold Seal award for nursing homes).

7. that the Legislature insert into F.S. Chapter 400, part II, and Chapter 395.1055(3), the inclusion of “good end-of-life care” as evidenced by a system to improve pain and symptom management, provide advanced care planning, and psycho/social support as a part of meeting the OBRA mandate of providing the “highest practicable level of care.”
8. that the Legislature add to F.S. Chapter 765.109, language to enhance protection for provider actions taken in accordance with the individual’s oral or written advance directive statements that have been expressed by a competent informed and uncoerced adult and appropriately activated; and that such language be added to the respective statutory provisions governing health care providers and health care entities.
9. that the Legislature provide for the portability of advance directives including a standard DNRO form that will be aligned with complementary public information and public education; establish a work group under the auspices of the end-of-life advisory panel to develop a standard DNRO form that will be accepted and used among all providers in the continuum of care. The advisory group will be comprised of the involved providers and a representative of the Elder Law Section of the Florida Bar.

[1 dissenting vote<sup>3</sup> ]

10. that the Legislature amend Florida Statute 430.707, Section 3(6), to extend the Panel for the Study of End-of-Life Care until August 1, 2000; add to Section 3(2),”(j) The Secretary of the Department of Health, or his designee”, to serve as an additional member; add to Section 3, (3) line 6: “with funds appropriated for administrative and operational expenses;” and delete from Section 3(5)”final” before “report by August 1, 1999 ...”
11. that the Legislature establish a working group made up of a representative from the Florida Legislature, staff representation from the House and Senate Appropriations committees, the Agency for Health Care Administration, the Department of Elder Affairs, the Department of Health, and representatives from the respective provider associations to examine reimbursement methodologies for end-of-life care such as consultative hospice service and a Medicaid case-mix reimbursement of palliative care, and to develop recommendations for incentives for appropriate end-of-life care of a high standard that will allow for more timely palliative and hospice care and enable all providers along the health-care continuum to participate in an excellent standard of end-of-life care.

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<sup>3</sup> Disagreement over the advisability of any type of form.

Appendix 4  
CS/CS/SB2228



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An act relating to end-of-life care; providing legislative findings; authorizing the Secretary of Health to develop and implement demonstration projects; requiring reports; requesting the Chancellor of the State University System to convene a working group; amending ss. 395.1041, 400.142, 400.4255, 400.487, 400.6095, 400.621, F.S.; authorizing personnel of hospital emergency services, long-term care facilities, assisted living facilities, home health agencies, hospices, and adult family-care homes to withhold or withdraw cardiopulmonary resuscitation pursuant to an order not to resuscitate; providing for rules; providing certain protection from prosecution and liability; amending s. 401.45, F.S.; revising authority of emergency medical technicians and paramedics to withhold or withdraw resuscitation or life-prolonging techniques; directing the Department of Health to develop a standardized do-not-resuscitate identification system; authorizing a fee; providing for rules; amending ss. 455.604, 458.319, 459.008, F.S.; providing that courses on end-of-life care will fulfill certain education requirements; amending s. 732.912, F.S.; revising provisions relating to who may make anatomical gifts; amending ss. 732.914, 732.917, F.S.; correcting cross-references; amending s. 732.922, F.S.; conforming



1 provisions relating to duty of certain hospital  
2 administrators; amending s. 765.101, F.S.;  
3 revising definitions; defining the terms  
4 "persistent vegetative state" and "end-stage  
5 condition"; amending s. 765.102, F.S.; revising  
6 legislative intent relating to advance  
7 directives; amending s. 765.103, F.S.;  
8 providing for effect of existing advance  
9 directives; amending s. 765.104, F.S.;  
10 providing for amendment of an advance directive  
11 or designation of a surrogate; amending s.  
12 765.107, F.S.; providing nonapplicability to  
13 certain persons; amending s. 765.110, F.S.;  
14 prohibiting certain actions by a health care  
15 facility or provider with respect to a  
16 patient's advance directive; increasing a  
17 penalty; requiring that advance directives  
18 become part of patients' medical records;  
19 providing for rules; amending s. 765.204, F.S.;  
20 revising provisions relating to evaluation of a  
21 patient's capacity to make health care  
22 decisions; amending s. 765.205, F.S.; revising  
23 responsibilities of the surrogate; amending s.  
24 765.301, F.S.; correcting a cross-reference;  
25 amending s. 765.302, F.S.; revising procedure  
26 for making a living will; amending s. 765.303,  
27 F.S.; revising suggested form of a living will;  
28 amending s. 765.304, F.S.; revising procedure  
29 for implementing a living will; amending s.  
30 765.305, F.S.; revising procedure in the  
31 absence of a living will; amending s. 765.306,

1 F.S.; revising provisions relating to  
2 determination of the patient's condition;  
3 renumbering and amending s. 765.308, F.S.;  
4 providing for transfer of a patient under  
5 certain circumstances; renumbering and amending  
6 s. 765.310, F.S.; providing penalties for  
7 falsification, forgery, or willful concealment,  
8 cancellation, or destruction of an advance  
9 directive, or a revocation or amendment  
10 thereof; amending s. 765.401, F.S.; revising  
11 provisions relating to decisions by a proxy;  
12 creating s. 765.404, F.S.; providing conditions  
13 for withholding or withdrawing life-prolonging  
14 procedures for certain persons in a persistent  
15 vegetative state; directing the Department of  
16 Elderly Affairs to convene a workgroup to  
17 develop model advance directive forms;  
18 providing effective dates.

19  
20 Be It Enacted by the Legislature of the State of Florida:

21  
22 Section 1. End-of-life care.--

23 (1) (a) The Legislature finds that Florida, as the  
24 fourth most populous state, is highly diverse with regard to  
25 race, ethnicity, urban and rural locales, religious practices,  
26 and cultural traditions. Florida has the largest percentage of  
27 elderly residents, the third largest incidence of AIDS, and  
28 the fourth highest death rates from heart disease and chronic  
29 obstructive pulmonary disease in the nation.

30 (b) The Legislature finds that the Panel for the Study  
31 of End-of-Life Care has recommended policies that will assure

1 | the citizens of this state the highest quality of  
2 | compassionate, competent, and adequate end-of-life care.

3 |         (c) The Legislature finds that all persons should have  
4 | access to effective pain management and palliative care; that  
5 | adequate management of pain and other distressing symptoms at  
6 | the end-of-life should be available; and that all settings  
7 | that care for seriously ill patients should address the  
8 | emotional and spiritual needs of such patients. The  
9 | Legislature finds that education of physicians and other  
10 | health care providers is necessary to assure that patients in  
11 | pain are assessed regularly and that their pain is treated  
12 | aggressively without fear of undue regulatory or legal action.

13 |         (d) The Legislature finds that an individual's  
14 | experience of death and dying, and preferences about  
15 | end-of-life care, are rooted in ethnic and cultural values and  
16 | beliefs. The Legislature finds that social, health, and  
17 | education practitioners must be trained to understand work  
18 | within different cultural parameters.

19 |         (e) The Legislature finds that to provide better pain  
20 | management, health care providers are to be encouraged to add  
21 | the assessment of pain as a "fifth vital sign." Further, the  
22 | Legislature intends that in accordance with standard and  
23 | accepted medical and ethical principles, the use of  
24 | pharmacological substances with the intent of alleviating or  
25 | eliminating pain and other discomfort is encouraged. Such use  
26 | should not be regarded as legally blameworthy, even if  
27 | appropriate pain control occurs during, and so precedes the  
28 | outcome of, the dying process.

29 |         (f) The Legislature finds that the State Supreme Court  
30 | has declared that, based on the constitutional right to  
31 | privacy, competent adults can express their wishes to receive,

1 | refuse, withhold, or withdraw any medical treatment and that  
2 | right continues even when a person becomes incapacitated.

3 |         (2) The Secretary of Health is authorized to develop  
4 | and implement up to two demonstration projects to evaluate  
5 | strategies recommended by the Panel for the Study of  
6 | End-of-Life Care. The Department of Health is authorized to  
7 | accept for that purpose any special grant of money, services,  
8 | property, gifts, or donations from any organization, medical  
9 | school, or Federal Government agency, and to apply for grants  
10 | to support the demonstration projects. The secretary shall  
11 | report to the President of the Senate, the Speaker of the  
12 | House of Representatives, and the majority and minority  
13 | leaders and relevant substantive committees of both chambers,  
14 | on the demonstration projects, no later than January 30 of  
15 | each year.

16 |         (3) The Chancellor of the State University System is  
17 | requested to convene a working group composed of one  
18 | representative from each of the Boards of Medicine,  
19 | Osteopathic Medicine, Nursing, Pharmacy, Nursing Home  
20 | Administrators, and Social Work, and the chairs of the four  
21 | medical schools' curriculum committees, to review available  
22 | curricula for end-of-life care and make recommendations  
23 | through the respective boards for content and materials to be  
24 | incorporated into the basic curriculum of each medical school,  
25 | school of social work, and allied health discipline.

26 |         Section 2. Paragraph (1) is added to subsection (3) of  
27 | section 395.1041, Florida Statutes, 1998 Supplement, to read:

28 |         395.1041 Access to emergency services and care.--

29 |         (3) EMERGENCY SERVICES; DISCRIMINATION; LIABILITY OF  
30 | FACILITY OR HEALTH CARE PERSONNEL.--

31 |

1           (1) Hospital emergency services personnel may withhold  
2 or withdraw cardiopulmonary resuscitation if presented with an  
3 order not to resuscitate executed pursuant to s. 401.45.  
4 Facility staff and facilities shall not be subject to criminal  
5 prosecution or civil liability, nor be considered to have  
6 engaged in negligent or unprofessional conduct, for  
7 withholding or withdrawing cardiopulmonary resuscitation  
8 pursuant to such an order.

9           Section 3. Section 400.142, Florida Statutes, is  
10 amended to read:

11           400.142 Emergency medication kits; orders not to  
12 resuscitate.--

13           (1) Other provisions of this chapter or of chapter  
14 465, chapter 499, or chapter 893 to the contrary  
15 notwithstanding, each nursing home operating pursuant to a  
16 license issued by the agency may maintain an emergency  
17 medication kit for the purpose of storing medicinal drugs to  
18 be administered under emergency conditions to residents  
19 residing in such facility.

20           (2) The agency shall adopt such rules as it may deem  
21 appropriate to the effective implementation of this act,  
22 including, but not limited to, rules which:

23           (a) Define the term "emergency medication kit."

24           (b) Describe the medicinal drugs eligible to be placed  
25 in emergency medication kits.

26           (c) Establish requirements for the storing of  
27 medicinal drugs in emergency medication kits and the  
28 maintenance of records with respect thereto.

29           (d) Establish requirements for the administration of  
30 medicinal drugs to residents under emergency conditions from  
31 emergency medication kits.

1 (3) Facility staff may withhold or withdraw  
2 cardiopulmonary resuscitation if presented with an order not  
3 to resuscitate executed pursuant to s. 401.45. The agency  
4 shall adopt rules providing for the implementation of such  
5 orders. Facility staff and facilities shall not be subject to  
6 criminal prosecution or civil liability, nor be considered to  
7 have engaged in negligent or unprofessional conduct, for  
8 withholding or withdrawing cardiopulmonary resuscitation  
9 pursuant to such an order and rules adopted by the agency.

10 Section 4. Section 400.4255, Florida Statutes, is  
11 amended to read:

12 400.4255 Use of licensed personnel; emergency care.--

13 (1) (a) Persons under contract to the facility,  
14 facility staff, or volunteers, who are licensed according to  
15 chapter 464, or those persons exempt under s. 464.022(1), and  
16 others as defined by rule, may administer medications to  
17 residents, take residents' vital signs, manage individual  
18 weekly pill organizers for residents who self-administer  
19 medication, give prepackaged enemas ordered by a physician,  
20 observe residents, document observations on the appropriate  
21 resident's record, report observations to the resident's  
22 physician, and contract or allow residents or a resident's  
23 representative, designee, surrogate, guardian, or attorney in  
24 fact to contract with a third party, provided residents meet  
25 the criteria for appropriate placement as defined in s.

26 400.426. Nursing assistants certified pursuant to s. 400.211  
27 may take residents' vital signs as directed by a licensed  
28 nurse or physician.

29 (b) All staff in facilities licensed under this part  
30 shall exercise their professional responsibility to observe  
31 residents, to document observations on the appropriate

1 resident's record, and to report the observations to the  
2 resident's physician. However, the owner or administrator of  
3 the facility shall be responsible for determining that the  
4 resident receiving services is appropriate for residence in  
5 the facility.

6 (c) In an emergency situation, licensed personnel may  
7 carry out their professional duties pursuant to chapter 464  
8 until emergency medical personnel assume responsibility for  
9 care.

10 (2) In facilities licensed to provide extended  
11 congregate care, persons under contract to the facility,  
12 facility staff, or volunteers, who are licensed according to  
13 chapter 464, or those persons exempt under s. 464.022(1), or  
14 those persons certified as nursing assistants pursuant to s.  
15 400.211, may also perform all duties within the scope of their  
16 license or certification, as approved by the facility  
17 administrator and pursuant to this part.

18 (3) Facility staff may withhold or withdraw  
19 cardiopulmonary resuscitation if presented with an order not  
20 to resuscitate executed pursuant to s. 401.45. The department  
21 shall adopt rules providing for the implementation of such  
22 orders. Facility staff and facilities shall not be subject to  
23 criminal prosecution or civil liability, nor be considered to  
24 have engaged in negligent or unprofessional conduct, for  
25 withholding or withdrawing cardiopulmonary resuscitation  
26 pursuant to such an order and rules adopted by the department.

27 Section 5. Section 400.487, Florida Statutes, is  
28 amended to read:

29 400.487 Patient assessment; establishment and review  
30 of plan of care; provision of services; orders not to  
31 resuscitate.--

1           (1) The home health agency providing care and  
2 treatment must make an assessment of the patient's needs  
3 within 48 hours after the start of services.

4           (2) The attending physician for a patient receiving  
5 care or treatment provided by a licensed nurse or by a  
6 physical, occupational, or speech therapist must establish a  
7 plan of care for the patient on behalf of the home health  
8 agency that provides services to the patient. The original  
9 plan of treatment must be signed by the physician and  
10 reviewed, at least every 62 days or more frequently if the  
11 patient's illness requires, by the physician in consultation  
12 with home health agency personnel that provide services to the  
13 patient.

14           (3) Each patient has the right to be informed of and  
15 to participate in the planning of his or her care. Each  
16 patient must be provided, upon request, a copy of the plan of  
17 care established and maintained for that patient by the home  
18 health agency.

19           (4) Home health services that are provided to a  
20 patient must be evaluated in the patient's home by a physician  
21 licensed under chapter 458, chapter 459, chapter 460, or  
22 chapter 461 or by a registered nurse licensed under chapter  
23 464 as frequently as necessary to assure safe and adequate  
24 care, but not less frequently than once every 62 days.

25           (5) A home health agency must provide at least one  
26 home health service to patients for whom it has agreed to  
27 provide care. Services provided by others under contractual  
28 arrangements to a home health agency's patients must be  
29 monitored and controlled by the home health agency.



1           (6) The services provided by a home health agency,  
2 directly or under contract, must be supervised and coordinated  
3 in accordance with the plan of care.

4           (7) Home health agency personnel may withhold or  
5 withdraw cardiopulmonary resuscitation if presented with an  
6 order not to resuscitate executed pursuant to s. 401.45. The  
7 agency shall adopt rules providing for the implementation of  
8 such orders. Home health personnel and agencies shall not be  
9 subject to criminal prosecution or civil liability, nor be  
10 considered to have engaged in negligent or unprofessional  
11 conduct, for withholding or withdrawing cardiopulmonary  
12 resuscitation pursuant to such an order and rules adopted by  
13 the agency.

14           Section 6. Present subsection (8) of section 400.6095,  
15 Florida Statutes, is renumbered as subsection (9), and a new  
16 subsection (8) is added to that section, to read:

17           400.6095 Patient admission; assessment; plan of care;  
18 discharge; death.--

19           (8) The hospice care team may withhold or withdraw  
20 cardiopulmonary resuscitation if presented with an order not  
21 to resuscitate executed pursuant to s. 401.45. The department  
22 shall adopt rules providing for the implementation of such  
23 orders. Hospice staff shall not be subject to criminal  
24 prosecution or civil liability, nor be considered to have  
25 engaged in negligent or unprofessional conduct, for  
26 withholding or withdrawing cardiopulmonary resuscitation  
27 pursuant to such an order and rules adopted by the department.

28           Section 7. Present subsection (3) of section 400.621,  
29 Florida Statutes, 1998 Supplement, is renumbered as subsection  
30 (4), and a new subsection (3) is added to that section, to  
31 read:

1           400.621 Rules and standards relating to adult  
2 family-care homes.--

3           (3) The department shall adopt rules providing for the  
4 implementation of orders not to resuscitate. The provider may  
5 withhold or withdraw cardiopulmonary resuscitation if  
6 presented with an order not to resuscitate executed pursuant  
7 to s. 401.45. The provider shall not be subject to criminal  
8 prosecution or civil liability, nor be considered to have  
9 engaged in negligent or unprofessional conduct, for  
10 withholding or withdrawing cardiopulmonary resuscitation  
11 pursuant to such an order and rules adopted by the department.

12           Section 8. Subsection (3) of section 401.45, Florida  
13 Statutes, is amended and subsection (5) is added to that  
14 section, to read:

15           401.45 Denial of emergency treatment; civil  
16 liability.--

17           (3)(a) Resuscitation or life-prolonging techniques may  
18 be withheld or withdrawn from a patient by an emergency  
19 medical technician or paramedic if evidence of an order not to  
20 resuscitate by the patient's physician is presented to the  
21 emergency medical technician or paramedic in a manner provided  
22 by rule of the department.

23           (b) Any licensee, physician, medical director, or  
24 emergency medical technician or paramedic who acts under the  
25 direction of a medical director is not subject to criminal  
26 prosecution or civil liability, and has not engaged in  
27 negligent or unprofessional conduct, as a result of the  
28 withholding or withdrawal of resuscitation or life-prolonging  
29 techniques from a patient pursuant to this subsection and  
30 rules adopted by the department.

1 (c) The department, in consultation with the  
2 Department of Elderly Affairs and the Agency for Health Care  
3 Administration, shall develop a standardized  
4 do-not-resuscitate identification system with devices that  
5 signify, when carried or worn, that the possessor is a patient  
6 for whom a physician has issued an order not to administer  
7 cardiopulmonary resuscitation. The department may charge a  
8 reasonable fee to cover the cost of producing and distributing  
9 such identification devices. Use of such devices shall be  
10 voluntary.

11 (5) The department shall adopt and enforce all rules  
12 necessary to implement this section.

13 Section 9. Subsection (9) is added to section 455.604,  
14 Florida Statutes, 1998 Supplement, to read:

15 455.604 Requirement for instruction for certain  
16 licensees on human immunodeficiency virus and acquired immune  
17 deficiency syndrome.--

18 (9) In lieu of completing a course as required in  
19 subsection (1), the licensee may complete a course in  
20 end-of-life care and palliative health care, so long as the  
21 licensee completed an approved AIDS/HIV course in the  
22 immediately preceding biennium.

23 Section 10. Subsection (4) is added to section  
24 458.319, Florida Statutes, 1998 Supplement, to read:

25 458.319 Renewal of license.--

26 (4) Notwithstanding the provisions of s. 455.604, a  
27 physician may complete continuing education on end-of-life  
28 care and palliative health care in lieu of continuing  
29 education in AIDS/HIV, if that physician has completed the  
30 AIDS/HIV continuing education in the immediately preceding  
31 biennium.

1 Section 11. Subsection (5) is added to section  
2 459.008, Florida Statutes, 1998 Supplement, to read:

3 459.008 Renewal of licenses and certificates.--

4 (5) Notwithstanding the provisions of s. 455.604, an  
5 osteopathic physician may complete continuing education on  
6 end-of-life and palliative health care in lieu of continuing  
7 education in AIDS/HIV, if that physician has completed the  
8 AIDS/HIV continuing education in the immediately preceding  
9 biennium.

10 Section 12. Section 732.912, Florida Statutes, 1998  
11 Supplement, is amended to read:

12 732.912 Persons who may make an anatomical gift.--

13 (1) Any person who may make a will may give all or  
14 part of his or her body for any purpose specified in s.  
15 732.910, the gift to take effect upon death. An anatomical  
16 gift made by an adult donor and not revoked by the donor as  
17 provided in s. 732.916 is irrevocable and does not require the  
18 consent or concurrence of any person after the donor's death.

19 (2) If the decedent has not executed an agreement  
20 concerning an anatomical gift, including signing an organ and  
21 tissue donor card, expressing his or her wish to donate in a  
22 living will or advance directive, or signifying his or her  
23 intent to donate on his or her driver's license or in some  
24 other written form has indicated his or her wish to make an  
25 anatomical gift, a member of one of the classes of persons  
26 listed below, in the order of priority stated and in the  
27 absence of actual notice of contrary indications by the  
28 decedent or actual notice of opposition by a member of the  
29 same or a prior class, the surrogate designated by the  
30 decedent pursuant to part II of chapter 765 may give all or  
31

1 | any part of the decedent's body for any purpose specified in  
2 | s. 732.910.:

3 |         (3) If the decedent has not executed an agreement  
4 | concerning an anatomical gift or designated a surrogate  
5 | pursuant to part II of chapter 765 to make an anatomical gift  
6 | pursuant to the conditions of subsection (2), a member of one  
7 | of the classes of persons listed below, in the order of  
8 | priority stated and in the absence of actual notice of  
9 | contrary indications by the decedent or actual notice of  
10 | opposition by a member of the same or a prior class, may give  
11 | all or any part of the decedent's body for any purpose  
12 | specified in s. 732.910:

- 13 |         (a) The spouse of the decedent;
- 14 |         (b) An adult son or daughter of the decedent;
- 15 |         (c) Either parent of the decedent;
- 16 |         (d) An adult brother or sister of the decedent;
- 17 |         (e) A grandparent of the decedent;
- 18 |         (f) A guardian of the person of the decedent at the  
19 | time of his or her death; or
- 20 |         (g) A representative ad litem who shall be appointed  
21 | by a court of competent jurisdiction forthwith upon a petition  
22 | heard ex parte filed by any person, which representative ad  
23 | litem shall ascertain that no person of higher priority exists  
24 | who objects to the gift of all or any part of the decedent's  
25 | body and that no evidence exists of the decedent's having made  
26 | a communication expressing a desire that his or her body or  
27 | body parts not be donated upon death;
- 28 |
- 29 | but no gift shall be made by the spouse if any adult son or  
30 | daughter objects, and provided that those of higher priority,  
31 | if they are reasonably available, have been contacted and made

1 aware of the proposed gift, and further provided that a  
2 reasonable search is made to show that there would have been  
3 no objection on religious grounds by the decedent.

4 (4)(3) If the donee has actual notice of contrary  
5 indications by the decedent or, in the case of a spouse making  
6 the gift, an objection of an adult son or daughter or actual  
7 notice that a gift by a member of a class is opposed by a  
8 member of the same or a prior class, the donee shall not  
9 accept the gift.

10 (5)(4) The person authorized by subsection (3) (2) may  
11 make the gift after the decedent's death or immediately before  
12 the decedent's death.

13 (6)(5) A gift of all or part of a body authorizes any  
14 examination necessary to assure medical acceptability of the  
15 gift for the purposes intended.

16 (7)(6) Once the gift has been made, the rights of the  
17 donee are paramount to the rights of others, except as  
18 provided by s. 732.917.

19 Section 13. Subsection (5) of section 732.914, Florida  
20 Statutes, 1998 Supplement, is amended to read:

21 732.914 Manner of executing anatomical gifts.--

22 (5) Any gift by a member of a class designated in s.  
23 732.912(3)(2) must be made by a document signed by that person  
24 or made by that person's witnessed telephonic discussion,  
25 telegraphic message, or other recorded message.

26 Section 14. Subsection (3) of section 732.917, Florida  
27 Statutes, is amended to read:

28 732.917 Rights and duties at death.--

29 (3) The organ procurement organization, tissue bank,  
30 or eye bank, or hospital medical professionals under the  
31 direction thereof, may perform any and all tests to evaluate

1 | the deceased as a potential donor and any invasive procedures  
2 | on the deceased body in order to preserve the potential  
3 | donor's organs. These procedures do not include the surgical  
4 | removal of an organ or penetrating any body cavity,  
5 | specifically for the purpose of donation, until a properly  
6 | executed donor card or document is located or, if a properly  
7 | executed donor card or document cannot be located, a person  
8 | specified in s. 732.912(3)(2) has been located, has been  
9 | notified of the death, and has granted legal permission for  
10 | the donation.

11 |         Section 15. Subsection (2) of section 732.922, Florida  
12 | Statutes, 1998 Supplement, is amended to read:

13 |             732.922 Duty of certain hospital administrators;  
14 | liability of hospital administrators, organ procurement  
15 | organizations, eye banks, and tissue banks.--

16 |             (2) Where, based on accepted medical standards, a  
17 | hospital patient is a suitable candidate for organ or tissue  
18 | donation, the hospital administrator or the hospital  
19 | administrator's designee shall, at or near the time of death,  
20 | access the organ and tissue donor registry created by s.  
21 | 732.915(4) to ascertain the existence of a donor card or  
22 | document executed by the decedent. In the absence of a donor  
23 | card, organ donation sticker or organ donation imprint on a  
24 | driver's license, or other properly executed document, the  
25 | hospital administrator or designee shall request:

26 |             (a) The patient's health care surrogate, as permitted  
27 | in s. 732.912(2); or

28 |             (b) If the patient does not have a surrogate, or the  
29 | surrogate is not reasonably available, any of the persons  
30 | specified in s. 732.912(3), in the order and manner of  
31 | priority stated in s. 732.912(3),

1  
2 to consent to the gift of all or any part of the decedent's  
3 body for any purpose specified in this part. Except as  
4 provided in s. 732.912, in the absence of actual notice of  
5 opposition, consent need only be obtained from the person or  
6 persons in the highest priority class reasonably available.

7 Section 16. Section 765.101, Florida Statutes, is  
8 amended to read:

9 765.101 Definitions.--As used in this chapter:

10 (1) "Advance directive" means a witnessed written  
11 document or oral statement in which instructions are given by  
12 a principal or in which the principal's desires are expressed  
13 concerning any aspect of the principal's health care, and  
14 includes, but is not limited to, the designation of a health  
15 care surrogate, a living will, or an anatomical gift made  
16 pursuant to part X of chapter 732 orders not to resuscitate  
17 issued pursuant to s. 401.45.

18 (2) "Attending physician" means the primary physician  
19 who has responsibility for the treatment and care of the  
20 patient.

21 (3) "Close personal friend" means any person 18 years  
22 of age or older who has exhibited special care and concern for  
23 the patient, and who presents an affidavit to the health care  
24 facility or to the attending or treating physician stating  
25 that he or she is a friend of the patient; is willing and able  
26 to become involved in the patient's health care; and has  
27 maintained such regular contact with the patient so as to be  
28 familiar with the patient's activities, health, and religious  
29 or moral beliefs.

30 (4) "End-stage condition" means a condition that is  
31 caused by injury, disease, or illness which has resulted in



1 | severe and permanent deterioration, indicated by incapacity  
2 | and complete physical dependency, and for which, to a  
3 | reasonable degree of medical certainty, treatment of the  
4 | irreversible condition would be medically ineffective.

5 |         (5) (4) "Health care decision" means:

6 |             (a) Informed consent, refusal of consent, or  
7 | withdrawal of consent to any and all health care, including  
8 | life-prolonging procedures.

9 |             (b) The decision to apply for private, public,  
10 | government, or veterans' benefits to defray the cost of health  
11 | care.

12 |             (c) The right of access to all records of the  
13 | principal reasonably necessary for a health care surrogate to  
14 | make decisions involving health care and to apply for  
15 | benefits.

16 |             (d) The decision to make an anatomical gift pursuant  
17 | to part X of chapter 732.

18 |         (6) (5) "Health care facility" means a hospital,  
19 | nursing home, hospice, home health agency, or health  
20 | maintenance organization licensed in this state, or any  
21 | facility subject to part I of chapter 394.

22 |         (7) (6) "Health care provider" or "provider" means any  
23 | person licensed, certified, or otherwise authorized by law to  
24 | administer health care in the ordinary course of business or  
25 | practice of a profession.

26 |         (8) (7) "Incapacity" or "incompetent" means the patient  
27 | is physically or mentally unable to communicate a willful and  
28 | knowing health care decision. For the purposes of making an  
29 | anatomical gift, the term also includes a patient who is  
30 | deceased.

31 |

1 (9) (8) "Informed consent" means consent voluntarily  
2 given by a person after a sufficient explanation and  
3 disclosure of the subject matter involved to enable that  
4 person to have a general understanding of the treatment or  
5 procedure and the medically acceptable alternatives, including  
6 the substantial risks and hazards inherent in the proposed  
7 treatment or alternative procedures, and to make a knowing  
8 health care decision without coercion or undue influence.

9 (10) (9) "Life-prolonging procedure" means any medical  
10 procedure, treatment, or intervention, including artificially  
11 provided sustenance and hydration, which sustains, restores,  
12 or supplants a spontaneous vital function. which:

13 (a) Utilizes mechanical or other artificial means to  
14 sustain, restore, or supplant a spontaneous vital function;  
15 and

16 (b) When applied to a patient in a terminal condition,  
17 serves only to prolong the process of dying.

18  
19 The term "life-prolonging procedure" does not include the  
20 administration of medication or performance of medical  
21 procedure, when such medication or procedure is deemed  
22 necessary to provide comfort care or to alleviate pain.

23 (11) (10) "Living will" or "declaration" means:

24 (a) A witnessed document in writing, voluntarily  
25 executed by the principal in accordance with s. 765.302; or

26 (b) A witnessed oral statement made by the principal  
27 expressing the principal's instructions concerning  
28 life-prolonging procedures.

29 (12) "Persistent vegetative state" means a permanent  
30 and irreversible condition of unconsciousness in which there  
31 is:

1 (a) The absence of voluntary action or cognitive  
2 behavior of any kind.

3 (b) An inability to communicate or interact  
4 purposefully with the environment.

5 (13) (11) "Physician" means a person licensed pursuant  
6 to chapter 458 or chapter 459.

7 (14) (12) "Principal" means a competent adult executing  
8 an advance directive and on whose behalf health care decisions  
9 are to be made.

10 (15) (13) "Proxy" means a competent adult who has not  
11 been expressly designated to make health care decisions for a  
12 particular incapacitated individual, but who, nevertheless, is  
13 authorized pursuant to s. 765.401 to make health care  
14 decisions for such individual.

15 (16) (14) "Surrogate" means any competent adult  
16 expressly designated by a principal to make health care  
17 decisions on behalf of the principal upon the principal's  
18 incapacity.

19 (17) (15) "Terminal condition" means:

20 (a) a condition caused by injury, disease, or illness  
21 from which there is no reasonable medical probability of  
22 recovery and which, without treatment, can be expected to  
23 cause death.; or

24 (b) A persistent vegetative state characterized by a  
25 permanent and irreversible condition of unconsciousness in  
26 which there is:

27 1. The absence of voluntary action or cognitive  
28 behavior of any kind; and

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

31

1           (16) "Treating physician" means the physician who has  
2 treated or is treating the patient for any condition directly  
3 related to the condition resulting in the patient's  
4 incapacity.

5           Section 17. Subsection (3) of section 765.102, Florida  
6 Statutes, is amended to read:

7           765.102 Legislative findings and intent.--

8           (3) The Legislature recognizes further finds that for  
9 some the administration of life-prolonging medical procedures  
10 may result in the artificial prolongation of life for a person  
11 with a terminal condition may secure for him or her only a  
12 precarious and burdensome existence, while providing nothing  
13 medically necessary or beneficial to the patient. In order to  
14 ensure that the rights and intentions of a person with such a  
15 condition may be respected even after he or she is no longer  
16 able to participate actively in decisions concerning himself  
17 or herself, and to encourage communication among such patient,  
18 his or her family, and his or her physician, the Legislature  
19 declares that the laws of this state recognize the right of a  
20 competent adult to make an advance directive instructing his  
21 or her physician to provide, withhold, or withdraw  
22 life-prolonging procedures, or to designate another to make  
23 the treatment decision for him or her in the event that such  
24 person should become incapacitated and unable to personally  
25 direct his or her medical care be found to be incompetent and  
26 suffering from a terminal condition.

27           Section 18. Section 765.103, Florida Statutes, is  
28 amended to read:

29           765.103 Existing advance directives.--Any advance  
30 directive made prior to October 1, 1999, April 10, 1992, shall  
31

1 | be given effect as executed, as provided in this chapter  
2 | provided such directive was legally effective when written.

3 |         Section 19. Section 765.104, Florida Statutes, is  
4 | amended to read:

5 |             765.104 Amendment or revocation.--

6 |             (1) An advance directive or designation of a surrogate  
7 | may be amended or revoked at any time by a competent  
8 | principal:

9 |             (a) By means of a signed, dated writing;

10 |            (b) By means of the physical cancellation or  
11 | destruction of the advance directive by the principal or by  
12 | another in the principal's presence and at the principal's  
13 | direction;

14 |            (c) By means of an oral expression of intent to amend  
15 | or revoke; or

16 |            (d) By means of a subsequently executed advance  
17 | directive that is materially different from a previously  
18 | executed advance directive.

19 |            (2) Unless otherwise provided in the advance directive  
20 | or in an order of dissolution or annulment of marriage, the  
21 | dissolution or annulment of marriage of the principal revokes  
22 | the designation of the principal's former spouse as a  
23 | surrogate.

24 |            (3) Any such amendment or revocation will be effective  
25 | when it is communicated to the surrogate, health care  
26 | provider, or health care facility. No civil or criminal  
27 | liability shall be imposed upon any person for a failure to  
28 | act upon an amendment or a revocation unless that person has  
29 | actual knowledge of such amendment or revocation.

30 |         Section 20. Section 765.107, Florida Statutes, is  
31 | amended to read:

1 765.107 Construction.--

2 (1) This chapter shall not be construed to repeal by  
3 implication any provision of s. 766.103, the Florida Medical  
4 Consent Law. For all purposes, the Florida Medical Consent  
5 Law shall be considered an alternative to provisions of this  
6 section.

7 (2) Procedures provided in this chapter permitting the  
8 withholding or withdrawal of life-prolonging procedures do not  
9 apply to a person who never had capacity to designate a health  
10 care surrogate or execute a living will.

11 Section 21. Section 765.110, Florida Statutes, is  
12 amended to read:

13 765.110 Health care facilities and providers;  
14 discipline.--

15 (1) A health care facility, pursuant to Pub. L. No.  
16 101-508, ss. 4206 and 4751, shall provide to each patient  
17 written information concerning the individual's rights  
18 concerning advance directives and the health care facility's  
19 policies respecting the implementation of such rights, and  
20 shall document in the patient's medical records whether or not  
21 the individual has executed an advance directive.

22 (2) A health care provider or health care facility may  
23 not require a patient to execute an advance directive or to  
24 execute a new advance directive using the facility's or  
25 provider's forms. The patient's advance directives shall  
26 travel with the patient as part of the patient's medical  
27 record.

28 (3) (2) A health care provider or health care facility  
29 shall be subject to professional discipline and revocation of  
30 license or certification, and a fine of not more than \$1,000  
31 \$500 per incident, or both, if the health care provider or

1 health care facility, as a condition of treatment or  
2 admission, requires an individual to execute or waive an  
3 advance directive.

4 (4) (3) The Department of Elderly Affairs for hospices  
5 and, in consultation with the Department of Elderly Affairs,  
6 the Department of Health for health care providers, and  
7 Rehabilitative Services and the Agency for Health Care  
8 Administration for hospitals, nursing homes, home health  
9 agencies, and health maintenance organizations, and the  
10 Department of Children and Family Services for facilities  
11 subject to part I of chapter 394 shall adopt rules to  
12 implement the provisions of the section.

13 Section 22. Subsection (2) of section 765.204, Florida  
14 Statutes, is amended to read:

15 765.204 Capacity of principal; procedure.--

16 (2) If a principal's capacity to make health care  
17 decisions for herself or himself or provide informed consent  
18 is in question, the attending physician shall evaluate the  
19 principal's capacity and, if the physician concludes that the  
20 principal lacks capacity, enter that evaluation in the  
21 principal's medical record. If the attending physician has a  
22 question as to whether concludes that the principal lacks such  
23 capacity, another physician shall also evaluate the  
24 principal's capacity. If the second physician agrees that the  
25 principal lacks the capacity to make health care decisions or  
26 provide informed consent, the health care facility shall enter  
27 both physician's evaluations in the principal's clinical  
28 record and, if the principal has designated a health care  
29 surrogate, shall notify such surrogate in writing that her or  
30 his authority under the instrument has commenced.

31

1 Section 23. Subsection (2) of section 765.205, Florida  
2 Statutes, is amended to read:

3 765.205 Responsibility of the surrogate.--

4 (2) The surrogate may authorize the release of  
5 information and clinical records to appropriate persons to  
6 ensure the continuity of the principal's health care and may  
7 authorize the transfer and admission, discharge, or transfer  
8 of the principal to or from a health care facility or other  
9 facility or program licensed under chapter 400.

10 Section 24. Section 765.301, Florida Statutes, is  
11 amended to read:

12 765.301 Short title.--Sections 765.302-765.309  
13 765.302-765.310 may be cited as the "Life-Prolonging Procedure  
14 Act of Florida."

15 Section 25. Subsection (1) of section 765.302, Florida  
16 Statutes, is amended to read:

17 765.302 Procedure for making a living will; notice to  
18 physician.--

19 (1) Any competent adult may, at any time, make a  
20 living will or written declaration and direct directing the  
21 providing, withholding, or withdrawal of life-prolonging  
22 procedures in the event that such person has a terminal  
23 condition, has an end-stage condition, or is in a persistent  
24 vegetative state suffers from a terminal condition. A living  
25 will must be signed by the principal in the presence of two  
26 subscribing witnesses, one of whom is neither a spouse nor a  
27 blood relative of the principal. If the principal is  
28 physically unable to sign the living will, one of the  
29 witnesses must subscribe the principal's signature in the  
30 principal's presence and at the principal's direction.

31



1 Section 26. Subsection (1) of section 765.303, Florida  
2 Statutes, is amended to read:

3 765.303 Suggested form of a living will.--

4 (1) A living will may, BUT NEED NOT, be in the  
5 following form:

6 Living Will

7 Declaration made this .... day of ....., 19 .... I,  
8 ....., willfully and voluntarily make known my desire that  
9 my dying not be artificially prolonged under the circumstances  
10 set forth below, and I do hereby declare that, : if at any time  
11 I am both mentally and physically incapacitated

12 ....(initial).... and I have a terminal condition  
13 or ....(initial).... and I have an end-state condition  
14 or ....(initial).... and I am in a persistent  
15 vegetative state

16  
17 and if my attending or treating physician and another  
18 consulting physician have determined that there is no  
19 reasonable medical probability of my recovery from such  
20 condition, I direct that life-prolonging procedures be  
21 withheld or withdrawn when the application of such procedures  
22 would serve only to prolong artificially the process of dying,  
23 and that I be permitted to die naturally with only the  
24 administration of medication or the performance of any medical  
25 procedure deemed necessary to provide me with comfort care or  
26 to alleviate pain.

27 It is my intention that this declaration be honored by  
28 my family and physician as the final expression of my legal  
29 right to refuse medical or surgical treatment and to accept  
30 the consequences for such refusal.

31

1 In the event that I have been determined to be unable  
2 to provide express and informed consent regarding the  
3 withholding, withdrawal, or continuation of life-prolonging  
4 procedures, I wish to designate, as my surrogate to carry out  
5 the provisions of this declaration:

6  
7 Name:.....  
8 Address:.....  
9 ..... Zip Code:..  
10 Phone:.....

11 I understand the full import of this declaration, and I  
12 am emotionally and mentally competent to make this  
13 declaration.

14 Additional Instructions (optional):  
15 .....  
16 .....  
17 .....

18 .....(Signed).....  
19 .....Witness.....  
20 .....Address.....  
21 .....Phone.....  
22 .....Witness.....  
23 .....Address.....  
24 .....Phone.....

25  
26 Section 27. Subsection (2) of section 765.304, Florida  
27 Statutes, is amended to read:

28 765.304 Procedure for living will.--  
29 (2) Before proceeding in accordance with the  
30 principal's living will, it must be determined that:

31

1 (a) The principal does not have a reasonable medical  
2 probability of recovering capacity competency so that the  
3 right could be exercised directly by the principal.

4 (b) The principal has a terminal condition, has an  
5 end-stage condition, or is in a persistent vegetative state.  
6 The principal's physical condition is terminal.

7 (c) Any limitations or conditions expressed orally or  
8 in a written declaration have been carefully considered and  
9 satisfied.

10 Section 28. Section 765.305, Florida Statutes, is  
11 amended to read:

12 765.305 Procedure in absence of a living will.--

13 (1) In the absence of a living will executed pursuant  
14 to s. 765.303, the decision to withhold or withdraw  
15 life-prolonging procedures from a patient may be made by a  
16 health care surrogate designated by the patient pursuant to  
17 part II unless the designation limits the surrogate's  
18 authority to consent to the withholding or withdrawal of  
19 life-prolonging procedures.

20 (2) Before exercising the incompetent patient's right  
21 to forego treatment, the surrogate must be satisfied that:

22 (a) The patient does not have a reasonable medical  
23 probability of recovering capacity competency so that the  
24 right could be exercised by the patient.

25 (b) The patient is both mentally and physically  
26 incapacitated with no reasonable medical probability of  
27 recovery, the patient has an end-stage condition, the patient  
28 is in a persistent vegetative state, or the patient's physical  
29 condition is terminal.

30 Section 29. Section 765.306, Florida Statutes, is  
31 amended to read:

1           765.306 Determination of patient condition.--In  
2 determining whether the patient has a terminal condition, has  
3 an end-stage condition, or is in a persistent vegetative state  
4 or may recover mental and physical capacity, or whether a  
5 medical condition or limitation referred to in an advance  
6 directive exists, the patient's attending or treating  
7 physician and at least one other consulting physician must  
8 separately examine the patient. The findings of each such  
9 examination must be documented in the patient's medical record  
10 and signed by each examining physician before life-prolonging  
11 procedures may be withheld or withdrawn.

12           Section 30. Section 765.308, Florida Statutes, is  
13 renumbered as section 765.1105, Florida Statutes, and amended  
14 to read:

15           765.1105 765.308 Transfer of a patient.--

16           (1) A health care provider or facility that refuses to  
17 comply with a patient's advance directive the declaration of a  
18 patient, or the treatment decision of his or her surrogate,  
19 shall make reasonable efforts to transfer the patient to  
20 another health care provider or facility that will comply with  
21 the directive declaration or treatment decision. This chapter  
22 does not require a health care provider or facility to commit  
23 any act which is contrary to the provider's or facility's  
24 moral or ethical beliefs concerning life-prolonging  
25 procedures, if the patient:

26           (a) Is not in an emergency condition;, and

27           (b) Has received written information upon admission  
28 informing the patient of the policies of the health care  
29 provider or facility regarding such moral or ethical beliefs.

30           (2) A health care provider or facility that is  
31 unwilling to carry out the wishes of the patient or the

1 treatment decision of his or her surrogate because of moral or  
2 ethical beliefs must within 7 days either:

3 (a) Transfer the patient to another health care  
4 provider or facility. The health care provider or facility  
5 shall pay the costs for transporting the patient to another  
6 health care provider or facility; or

7 (b) If the patient has not been transferred, carry out  
8 the wishes of the patient or the patient's surrogate, unless  
9 the provisions of s. 765.105 apply.

10 Section 31. Section 765.310, Florida Statutes, is  
11 renumbered as section 765.1115, Florida Statutes, and amended  
12 to read:

13 765.1115 765.310 Falsification, forgery, or willful  
14 concealment, cancellation, or destruction of directive  
15 declaration or revocation or amendment; penalties.--

16 (1) Any person who willfully conceals, cancels,  
17 defaces, obliterates, or damages an advance directive a living  
18 will without the principal's consent or who falsifies or  
19 forges the revocation or amendment of an advance directive a  
20 revocation of a living will of another, and who thereby causes  
21 life-prolonging procedures to be utilized in contravention of  
22 the previously expressed intent of the principal, commits a  
23 felony of the third degree, punishable as provided in s.  
24 775.082, s. 775.083, or s. 775.084.

25 (2) Any person who falsifies or forges the advance  
26 directive living will of another or who willfully conceals or  
27 withholds personal knowledge of the revocation of an advance  
28 directive a declaration, with the intent to cause a  
29 withholding or withdrawal of life-prolonging procedures  
30 contrary to the wishes of the principal, and who thereby  
31 because of such act directly causes life-prolonging procedures

1 to be withheld or withdrawn and death to be hastened, commits  
2 a felony of the second degree, punishable as provided in s.  
3 775.082, s. 775.083, or s. 775.084.

4 Section 32. Subsection (3) of section 765.401, Florida  
5 Statutes, is amended to read:

6 765.401 The proxy.--

7 (3) Before exercising the incapacitated patient's  
8 rights to select or decline health care, the proxy must comply  
9 with the pertinent provisions applicable to surrogates under  
10 this chapter, except that a proxy's decision to withhold or  
11 withdraw life-prolonging procedures must either:

12 (a) Be supported by a written declaration; or

13 (b) If there is no written declaration, the patient  
14 must have a terminal condition, have an end-stage condition,  
15 or be in a persistent vegetative state, and the proxy's  
16 decision must be supported by clear and convincing evidence  
17 that the decision would have been the one the patient would  
18 have chosen had the patient been competent.

19 Section 33. Section 765.404, Florida Statutes, is  
20 created to read:

21 765.404 Persistent vegetative state.--For persons in a  
22 persistent vegetative state, as determined by the attending  
23 physician in accordance with currently accepted medical  
24 standards, who have no advance directive and for whom there is  
25 no evidence indicating what the person would have wanted under  
26 such conditions, and for whom, after a reasonably diligent  
27 inquiry, no family or friends are available or willing to  
28 serve as a proxy to make health care decisions for them,  
29 life-prolonging procedures may be withheld or withdrawn under  
30 the following conditions:

31

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

4           (2) The guardian and the person's attending physician,  
5 in consultation with the medical ethics committee of the  
6 facility where the patient is located, conclude that the  
7 condition is permanent and that there is no reasonable medical  
8 probability for recovery and that withholding or withdrawing  
9 life prolonging procedures is in the best interest of the  
10 patient. If there is no medical ethics committee at the  
11 facility, the facility must have an arrangement with the  
12 medical ethics committee of another facility or with a  
13 community-based ethics committee approved by the Florida  
14 Bio-ethics Network. The ethics committee shall review the case  
15 with the guardian, in consultation with the person's attending  
16 physician, to determine whether the condition is permanent and  
17 there is no reasonable medical probability for recovery. The  
18 individual committee members and the facility associated with  
19 an ethics committee shall not be held liable in any civil  
20 action related to the performance of any duties required in  
21 this subsection.

22           Section 34. The Department of Elderly Affairs shall  
23 convene a workgroup composed of health care professionals,  
24 health facilities, attorneys, consumers, clergy, academic  
25 institutions, and other interested parties to develop model  
26 advance directive forms. The department shall make the forms  
27 available to the public. The department may reconvene the  
28 workgroup as necessary to modify and update such forms.

29           Section 35. Except as otherwise expressly provided in  
30 this act, this act shall take effect October 1, 1999.

31

## Appendix 5

### Legislative History of CS/CS/SB 2228





In the Senate:

S 228 GENERAL BILL/CS/CS/1ST ENG by Judiciary; Health, Aging and Long-Term Care; Klein (Similar HOUSE 0343, HOUSE 2131, Compare HOUSE 0249, SENATE 1240, SENATE 1722)

End-of-life Care; authorizes personnel of hospital emergency services, long-term care & assisted living facilities, home health agencies, hospices, & adult family-care homes to withhold or withdraw cardiopulmonary resuscitation pursuant to order not to resuscitate; revises authority of emergency medical techniques, etc. Amend FS  
EFFECTIVE DATE: 10/01/1999 except as otherwise expressly provided.

03/02/99 SENATE Filed

03/16/99 SENATE Introduced, referred to Health, Aging and Long-Term Care; Judiciary; Fiscal Policy -SJ 00270

03/18/99 SENATE On Committee agenda-- Health, Aging and Long-Term Care, 03/23/99, 1:00 pm, Room-110S --Temporarily postponed

03/25/99 SENATE On Committee agenda-- Health, Aging and Long-Term Care, 03/30/99, 2:00 pm, Room-110S

03/30/99 SENATE Comm. Action: CS by Health, Aging and Long-Term Care -SJ 00436; CS read first time on 04/06/99 -SJ 00449

03/31/99 SENATE Now in Judiciary -SJ 00436

04/02/99 SENATE On Committee agenda-- Judiciary, 04/07/99, 2:00 pm, Room-110S

04/07/99 SENATE Comm. Action: CS/CS by Judiciary -SJ 00513; CS read first time on 04/13/99 -SJ 00518

04/09/99 SENATE Now in Fiscal Policy -SJ 00513

04/14/99 SENATE On Committee agenda-- Fiscal Policy, 04/19/99, 1:00 pm, Room-12K

04/19/99 SENATE Comm. Action:-Favorable with 1 amendment(s) by Fiscal Policy -SJ 00638

04/20/99 SENATE Placed on Calendar -SJ 00638

04/26/99 SENATE Placed on Special Order Calendar -SJ 00887

04/27/99 SENATE Placed on Special Order Calendar -SJ 00886, -SJ 01222

04/28/99 SENATE Placed on Special Order Calendar -SJ 01221, -SJ 01402

04/29/99 SENATE Placed on Special Order Calendar -SJ 01402, -SJ 01628; Read second time -SJ 01414; Amendment(s) adopted -SJ 01415; Read third time -SJ 01415; CS passed as amended; YEAS 37 NAYS 0 -SJ 01415

04/29/99 HOUSE In Messages

04/30/99 HOUSE Received -HJ 02017; Read second and third times -HJ 02017; CS passed; YEAS 116 NAYS 0 -HJ 02017

04/30/99 SENATE Ordered enrolled -SJ 01927

05/28/99 Signed by Officers and presented to Governor

06/11/99 Approved by Governor; Chapter No. 99-331

In the House:

04/06/99 HOUSE Filed; Introduced

04/08/99 HOUSE Referred to Judiciary; Health & Human Services Appropriations

04/13/99 HOUSE On Committee agenda-- Judiciary

04/15/99 HOUSE Comm. Action: Unanimously Favorable with 1 amendment(s) by  
Judiciary  
04/19/99 HOUSE Now in Health & Human Services Appropriations  
04/21/99 HOUSE Withdrawn from Health & Human Services Appropriations; Placed on  
calendar, available for General Calendar  
04/22/99 HOUSE Placed on Special Order Calendar  
04/23/99 HOUSE Placed on Special Order Calendar; Temporarily postponed, on Second  
Reading  
04/30/99 HOUSE Died on Calendar, Iden./Sim./Compare Bill(s) passed, refer to  
CS/CS/SB 2228 (Ch. 99-331)

## Appendix 6

### Minutes of Panel and Working Group Meetings



**Minutes of The Panel for the Study of End-of-Life Care**  
**Tuesday, July 28, 1998**  
**Room 214, Pepper Center, Florida State University Tallahassee, Florida**

**Panel Members in Attendance:**

Susan Acker, AHCA (for Marshall Kelley)  
Samira Beckwith, President, Hospice  
Rep. Bob Brooks, Florida House of Representatives  
Marie Cowart, faculty member, Florida State University  
Cathy Emmett, Fla. Nursing Association  
Joan Fulbright, Orlando Regional Medical Center  
Stan Godleski, former state director of AARP  
Mary Labyak, Director of SE Fla. Hospice  
Bentley Lipscomb, Secretary, Department of Elder Affairs  
LuMarie Polivka-West, Florida Health Care Association  
Jackie Roberts, Commission on Aging with Dignity (for Jim Towey)  
Ken Rubin, Florida Bar  
Marshall Seiden, Vice President, Florida Homes for the Aging  
Howard Tuch, physician (connected by conference call)  
Susan White, Florida Hospital Association  
Gary Winchester, Board of Medicine

**Observers in Attendance:**

Ramona D. Shedroff, Older Women's League of SE Florida  
Mary Bennett Hutson, Older Women's League of SE Florida  
Martha Russell, FADONA Board, Tampa  
Wandale Carter, Florida Senate Health Care Committee  
Kate Callahan, HCG  
Bennett Napier, Florida Life Care Residents Association, Tallahassee  
John R. Ridge, FMA, Tallahassee  
June L. Noel, Department of Elder Affairs, Tallahassee  
Gina Carreno, Sociology Graduate Student, FSU  
Tanya Williams, Florida Board of Medicine, Tallahassee  
Dana Crosby, Senate CFS Committee, Tallahassee  
Elizabeth Connor, Florida Healthtrac  
Mike Bittman, Health Law Section, Florida Bar, Orlando  
Patricia Inmon, Florida Assisted Living Association, Tallahassee  
Lynne Fagan, FHCA and the Long Term Care Commission, Daytona Beach  
Karen Peterson, Association of Community Hospitals, Tallahassee  
Cam Fentriss, Florida Hospices, Inc., Tallahassee  
Julie Kates, Florida Hospices, Inc., Tallahassee  
Molly McKinstry, Florida Association of Homes for Aging, Tallahassee  
Bill Bell, Florida Hospital Association, Tallahassee  
Susan Lampman, Center for Professional Development, FSU  
Mary Pat Moore, House of Representatives, Government Services Council, Tallahassee

**Facilitator:**

Peter Benjamin

I. Melissa Hardy, Director of the Pepper Institute, opened the meeting and introduced the facilitator, Peter Benjamin, who outlined his role as follows:

1. Help the Panel to adhere to the schedule
2. Help involve all Panel members
3. Stimulate conversation
4. Meeting logistics

II. After all Panel members introduced themselves to the group and the observers, the facilitator continued the meeting by outlining the specific mission of the Panel and the Legislative directives to be addressed:

Mission: to study the issues related to care provided to persons at the end of life

- a. methods to ensure that pain management is a goal of all pertinent providers
- b. identify barriers to adequate pain management
- c. analyze the merit in establishing new requirements in licensure and re-licensure of health care professionals to ensure adequate pain management
- d. ensure that adequate and complete advance directives are followed by health care providers
- e. identify potential regulatory and financial issues that could impede adequate end-of-life care in Florida

Deliverables required:

- a. Preliminary (interim) report presented by January 31, 1999
- b. Final report presented by August 1, 1999

III. Organizational Issues of the Panel:

1. Role and responsibilities of Chairperson and election of that person
2. Frequency of meetings and forums/types of meetings
3. Committee Structure and facilitation of reports
4. Composition of advisory board to advise Panel members
5. Funding
6. Activities of Panel participants
7. Expenses
8. Support from Pepper Institute on Aging and Public Policy
9. Press Relations
10. Notifying public of meetings
11. Expectation setting and ground rules for participation and attendance of Panel members
12. Attendance and participation of staff

IV. Discussion followed concerning the role/responsibilities of a Chairperson. Panel members contributed the following points and agreed on these duties as the responsibilities of the elected Chairperson:

1. Responsible for press relations and spokesperson for the Panel
2. Ensure that all points of view are brought out
3. Ensure agenda is established and sent out to all Panel members
4. Keep Panel focused on goals and deliverables
5. Preside at meetings
6. Understand overall administrative process
7. Move beyond individual issues, assure global perspective: extend the discussion beyond those in the room
8. Leadership and motivational ability: someone who can inspire people to give their best
9. Serve as spokesperson to Legislature requiring reports (and other groups)
10. Have the time to serve as Chairperson of the Panel

Rep. Bob Brooks was nominated for Chairperson; the nomination was seconded; and he was elected by acclamation.

V. Bentley Lipscomb suggested the Panel elect a Deputy Chairperson. The Panel concurred. Nominations were requested from the Panel. The nomination of Marie Cowart was made and seconded. The nomination of Bentley Lipscomb was made and seconded. The vote was called by the facilitator and Bentley Lipscomb was elected by a vote of 8-7 to serve as Deputy Chairperson of the Panel.

The Panel agreed that the Deputy Chairperson would

1. act in place of the Chairperson in all duties where the Chairperson cannot be present, during any absences of the Chairperson, or at the request of the Chairperson
2. work cooperatively with the Chairperson to meet the goals of the Panel

VI. Major issues to be considered by the Panel include

1. Education of professionals and the public
2. Advance directives
3. Surrogate
4. Defining delivery
5. Institutional boundaries
6. Legislative directives

VII. It was determined that the Panel would act as a committee of the whole but be divided into work groups with specific work topics. After discussion as to composition and focus of work groups, it was agreed by acclamation that they are to be linked to the topics specifically included the legislation:

Group 1 would cover topics in sections a, b, and c (pain management points).

Group 2 would cover topic in section d (advance directives).

Group 3 would cover topic in section e (regulatory and financial issues).



It was further decided that there should be a Chairperson for each work group. To determine the composition of each work group, Panel members chose an assignment.

Rep. Brooks pointed out the importance of including people with the most expertise in certain work groups. It was recommended that the Chairperson review the work group participants and be prepared to request work group reassignments among participants.

Other items discussed specific to work groups and individual participation included the following:

- Members should serve in work groups based on their expertise in certain areas, not just on their interest in a certain topic
- Members should serve in only one work group because of logistics
- Members should remember they are to contribute to the public good
- Work groups would serve to advise the whole when reporting back to the Panel
- Work groups are created by the Panel and their work will be brought back to Panel for approval
- Work groups will elect a Chair/leader

The Panel agreed that the Chair has the directive to contact other members of the Panel and discuss organization of work groups. The Chair, in conjunction with staff will contact the Panel members who are not in attendance.

VIII. It was suggested that the Panel discuss the meaning of end-of-life care but this should be the topic of a meeting. This definition should emerge as the Panel does its work and include (1) language of the legislation, (2) policy statement and intent.

IX. Advisory Board:

The Panel endorsed the development of an Advisory Board. Work groups are to think about possible members. Pepper Institute on Aging will serve as clearinghouse. Members need to provide information on background, etc. for any potential Advisory Board members to Melissa Hardy. Possible candidates for an advisory board include EMS (specifically related to advance directives), representatives of pharmaceutical companies, clergy. The Advisory Board/Group will be as inclusive as possible. As new issues evolve new members would be added.

Candidates for Advisory Board should include the various race/ethnic groups in Florida. It was brought to the attention of the group that the public may assume that the End-of-Life Care Panel is only for the elderly, but this is not true. It encompasses all age groups. Panel is not age-, culture-, or ethnicity-specific.

X. Meetings:

It was proposed that the next meeting be held in Tallahassee with the first formal meeting in the state (public hearing) and Panel meeting occurring on September 14th. It was felt that there should be some forms of public participation before the interim report

is due. Discussion followed concerning public hearings and geographic locations for such meetings. The wish list of geographic areas includes:

1. Dade/Broward
2. Panhandle/Pensacola/Tallahassee
3. Tampa/St. Petersburg/Pasco
4. Orlando
5. Ft. Myers
6. Palm Beach/Indian River
7. Volusia/Brevard
8. Duval

Three public meetings and a working meeting in early January are to precede the interim report. Two proposed locations are: Dade/Broward and Tampa/St. Pete

#### XI. Staffing and Funding:

Pepper Institute on Aging can provide limited staff support. The Panel currently has no legislative funding. Secretary Lipscomb has provided \$10,000, which is the current administrative budget. Melissa Hardy reported that one quarter of that has been expended. Members' individual organizations are to fund travel for Panel members. A concern was also expressed about the cost of renting/obtaining meeting space and equipment incurred to hold the meetings/public hearings. The organizations and their representatives here have something to gain by being involved. The Chair addressed the issue of funding from additional sources: The Institute has applied for a grant that would not be for direct travel expenses, but for some of the staff and administrative expenses. The small budget could limit the work of the Panel.

As a specific point, Samira Beckwith indicated that Hospice is very committed and wants to know what some of the needs are when talking with board members. It would be helpful to know specific needs when requesting money. It was recommended that the Institute work with Secretary Lipscomb to prepare cost estimates for public hearings in all eight geographic locations on the wish list. These cost estimates should include staff support (administrative overhead), anything other than travel.

#### XII. Frequency of meetings:

Suggested format for future meetings is that the Panel meet in the morning, then divide into working groups then reconvene for a Panel meeting in the afternoon. This proposal was approved by acclamation. The first activity is to give the work groups their marching orders. Then the work groups will elect a Chair/leader. Finally the work groups will report back to the Panel at the end of the day. This meeting day will not include a public hearing. It is recommended that the next meeting be held August 17. The Institute in consultation with the Chair will make recommendation for the meeting. Melissa Hardy will get back with everyone on time and location details.

The next meetings will be in September, October, and November and should include public hearings. It is proposed that these meetings span two days, with each day at a different location. This would facilitate covering all geographic locations mentioned earlier. It was noted that the required notification for the regular meeting is 7 days prior.

Notice for public hearings is 3 weeks prior. It is recommended that there be no public hearings in December. There should be a meeting in December and/or January to finalize the interim report to the Legislature.

XIII. Attendance and participation of Panel members:

Policy statement on attendance:

1. expectation is that all Panel members attend all meetings;
2. given that the Panel is a policy group, not a regulatory group, the specified organizations will be asked to appoint alternate delegates who will have voting rights. The Panel member is responsible for ensuring that the alternate is briefed before attending any meetings. The Panel agreed on the majority attendance as outlined above. The Chair suggests that each delegate have one vote with principle or alternate attending. A vote on the final product requires that the Panel member/alternate have attended the majority of meetings.

XIV. Regarding communication with the press and the public:

The Chair will be responsible for contact with the Press. Each Panel member can speak in his or her own behalf, but the Chair speaks for the Panel as a whole. Need to say at the outset that it is your own opinion, not the opinion of the Panel.

XV. How to proceed:

It was agreed that the Panel members should recommend information that will be needed for Panel deliberations and forward them to Melissa Hardy who will organize the requests for the next meeting. Some Panel members have information that can be shared with other members. Specifically concerning advance directives, Secretary Lipscomb indicated that EMS has put together information so they could brief the working group.

In summary, the next meeting will be held on August 17 from 9 a.m. to 4:30 p.m. in Tallahassee, with the place to be determined.

Rep. Brooks expressed his thanks to the Panel for working through such a demanding schedule today. The Chair asked the Panel members to go back to their respective organizations and request support. Rep. Brooks volunteered to help request funding assistance.

The meeting was adjourned.

A copy of the meeting agenda is attached for information purposes.

A copy of the list of observers is attached for archival purposes.

**Minutes of The Panel for the Study of End-of-Life Care**  
**Monday, August 17, 1998**  
**Room 225, Dept. of Elder Affairs Tallahassee, Florida**

**Panel Members in Attendance:**

David Abrams for Jack Gordon, Hospice Foundation of America  
Samira Beckwith, Florida Hospices  
Representative Bob Brooks, Florida House of Representatives  
Marie Cowart, Florida State University  
Joan Fulbright, Association of Community Hospitals & Health Systems  
Stan Godleski, Consumer Advocate  
Marshall Kelley, Agency for Health Care Administration  
Senator Ron Klein, Florida Senate  
Mary Labyak, Hospice of Florida Suncoast  
E. Bentley Lipscomb, Dept. of Elder Affairs  
LuMarie Polivka-West, Florida Health Care Association  
Jackie Roberts for Jim Towey, Commission on Aging with Dignity  
Kenneth Rubin, Florida Bar  
Leo Sandon, Florida State University  
Marshall Seiden, Florida Association of Homes for the Aging  
Howard Tuch, M.D., Florida Health Care Association  
Susan White, Florida Hospital Association  
Tanya Williams (for Doctors Winchester and Murray, Board of Medicine)

**Observers in Attendance:**

Susan Acker, Agency for Health Care Administration (HQA)  
Meta Calder, Dept. of Elder Affairs  
Kate Callahan, Pepper Institute on Aging  
June L. Noel, Dept. of Elder Affairs  
Cam Fentriss, Florida Hospices, Inc.  
Michael Haney, Children's Medical Services  
P.K. Jameson, Dept. of Elder Affairs  
Julie Kates, Florida Hospices, Inc.  
Molly McKinstry, Florida Association of Homes for the Aging  
Wavene Poole, Agency for Health Care Administration  
Karen Peterson, Association of Community Hospitals  
Freida B. Travis, Dept. of Health/Bureau of Emergency Medical Services  
Paul J. Williams, Florida Assisted Living Association

**Staff:**

Tom Batchelor, House Committee on Long Term Care  
Melissa Hardy, Pepper Institute on Aging and Public Policy  
Melanie Meyer, House Committee on Long Term Care

The meeting was called to order at 9:06 AM by Chairman, Dr. Bob Brooks. Alternate Panel members and new Panel members were introduced.

Dr. Brooks described the format for the workgroups that had been established at the last meeting and thanked those who provided refreshments. All Panel members were

reminded to recommend potential Advisory Board members from areas related to the Panel's mission and forward names and background information to Melissa Hardy.

A **MOTION** was made to accept the Minutes of the last meeting with corrections. Motion was seconded and passed unanimously.

Dr. Brooks informed the Panel that Roberts Rules of Order will be used for all future meetings. Discussion took place regarding whether or not public hearing meetings should require a quorum.

A **MOTION** was made that the public forums throughout the state will not require a quorum in order to meet and receive public input. Motion was seconded and passed unanimously.

Dr. Brooks gave an overview of the three workgroups - Pain Management, Advance Directives, and Regulatory and Financial Issues. Appropriate changes and recommendations were discussed. Workgroups will request changes if they identify problems.

Dr. Alvin Smith, representing the Florida Medical Association, was introduced to the Panel.

#### **Future meetings:**

A **MOTION** was made that the September meeting take place on September 15 in Orlando. Motion was seconded and passed unanimously.

A **MOTION** was made that the October meetings be held October 26 and 27. Motion was seconded and passed unanimously.

A **MOTION** was made that the October meeting follow the following format: First day - morning meeting (forum) in Dade County, evening meeting (forum) in Broward County; second day - morning meeting (forum) in Palm Beach County, afternoon meeting for Panel members. Motion was seconded and passed unanimously.

A **MOTION** was made that the November meeting take place on November 9 and 10. An **AMENDMENT** was offered that it take place on November 12 and 13. The Amendment was withdrawn. Motion was seconded and passed unanimously.

The need for the Panel and the Advisory Board to reflect the state's diversity was discussed.

A **MOTION** was made that the November meeting follow the following format: November 9 - morning meeting (forum) in Sarasota, evening meeting (forum) in Tampa/St. Pete area, November 10 - morning meeting (forum) in Pasco, afternoon meeting for Panel members. Motion was seconded and passed unanimously.

A **MOTION** was made that the December meeting take place December 4. Motion was seconded and passed unanimously.

A **MOTION** was made that the December meeting be held in North Florida; details to be determined by staff. Motion was seconded and passed unanimously.

Discussion took place regarding allowing adequate administrative staff time for the purpose of developing the Interim Report (due January 31, 1999) and the need to accommodate various calendars including the Legislative Calendar.

A **MOTION** was made that the January meeting take place on January 5 in Tallahassee at the Dept. of Elder Affairs, unless that date conflicts with the Legislative Calendar. Motion was seconded and passed unanimously.

### **Working Group Framework/Expectations/Marching Orders:**

Dr. Brooks outlined the following guidelines for workgroups to follow:

1. Any meetings must be open, noticed, and minutes kept.
2. Elect chairperson/group leader.
3. Take minutes – designate person.
4. Decide the issues.
5. Determine what areas of expertise would be most beneficial to workgroup.
6. Determine the types of data needed for workgroup - research, commentary, etc.
7. Determine whether groups can/will meet/conference call at additional times other than dates for full Panel meetings.
8. Although informal, groups should try to follow Roberts Rules of Order.

It was suggested that workgroups refer topics to other workgroups as appropriate. Workgroup meetings convened.

Panel members reassembled after workgroup meetings concluded. Dr. Brooks introduced Tom Cooper, Attorney for the House Government Services Council, who gave an overview of the Sunshine Law and its application to this Panel. He explained that subcommittees/workgroups also come under this law and explained the following requirements:

1. Meetings must be open to the public.
2. Reasonable notice must be given of such meetings.
3. Minutes must be recorded at meetings.

Dr. Brooks again reminded the Panel of the need for Advisory Board members and suggested that a list be formalized by the next meeting so that these members could be involved at the earliest possible time.

The Panel was advised that alternates may attend meetings along with members of the Panel; however, only Panel members would have the one vote agreed upon. A list of alternates should be finalized by the next meeting. Minority representation was encouraged when considering alternate members.

The budget was distributed. Dr. Brooks reiterated decisions made at the last meeting and reviewed the budget. He offered his assistance by way of calling Panel members' organizations to explain the need to fund committee costs. Marshall Kelley explained

that AHCA could possibly offer some assistance in the way of staff & some administrative costs. Marshall Seiden offered staff support and assistance with mailings. Dr. Brooks will look into possible support from the House. Other areas and methods of procuring resources were discussed.

### **Workgroup Reports:**

Financial/Regulatory Issues Workgroup - LuMarie Polivka-West gave an overview of the meeting. Key points reviewed were: continuum of care, problems, determinants, barriers, a need for education, and regulatory/financial influences that affect all points. It was reported that the Financial Regulatory Workgroup would be including EMS and Practice Parameters as areas of expertise needed, and that the Agency for Health Care Administration could provide presentations on both.

Dr. Brooks recommended that if persons with a particular expertise would be required to address the Panel on several occasions, that they be added to the Panel by way of his invitation. All were encouraged to advise him (through Melissa Hardy) of those persons by next week via phone or email so they could be included in the September meeting.

Dr. Brooks explained several future goals of the Panel. Emphasis was directed toward each workgroup presenting their issues with a distinct focus. Discussion took place and recommendations were presented regarding narrowing the focus of the workgroups to solutions rather than concerns.

It was suggested that representatives of the Department of Insurance and the HMO organizations be invited to be on the Advisory Board.

Advance Directives Workgroup - Kate Cowling gave an overview of the group's discussion and concerns. Key points reviewed were: the need for a physician in the workgroup, definition of terms, medical technology, informed consent, values and ethics, personal autonomy, managed care, religious aspects, physician & individual education. Further recommendations/considerations from the Panel were requested.

Pain Management Workgroup - Dr. Howard Tuch gave an overview of the workgroup's meeting. Key points included: clinical standards/guidelines, educational needs (professional and non-professional), access to pain management, diverse populations, barriers with laws & regulations, and systems of pain management.

Several suggestions for advisors regarding pain management were offered by Panel members. Dr. Brooks again reminded everyone to submit names of potential advisors to him by end of the week so they can be asked to attend the next meeting.

It was suggested that the majority of work time during the next Panel meeting be given to the workgroups.

A Study from the University of Florida regarding advance directives and statutory reference was discussed. June Noel, from the Department of Elder Affairs, offered to research obtaining the report.

Melissa Hardy requested that group leaders submit an outline of major issues discussed in their workgroups to her office as soon as possible.

A **MOTION** was made to adjourn. Seconded and passed unanimously.

The meeting was adjourned at 3:45 PM.



**Minutes of The Panel for the Study of End-of-Life Care**  
**Tuesday, September 15, 1998**  
**Beardall Center, 800 S. Delaney Avenue Orlando, FL**

**Panel Members in Attendance:**

Samira Beckwith, Florida Hospices  
Representative Dr. Bob Brooks, Florida House of Representatives  
Cathy Emmett, Florida Nurses Association  
Joan Fulbright, Association of Community Hospitals & Health Systems  
Stan Godleski, Consumer Advocate  
Marshall Kelley, Agency for Health Care Administration  
Mary Labyak, Hospice of Florida Suncoast  
E. Bentley Lipscomb, Dept. of Elder Affairs  
Belita Moreton, Florida League of Health Systems  
Dr. Louis Murray for Dr. Gary Winchester, Board of Medicine  
LuMarie Polivka-West, Florida Health Care Association  
Kenneth Rubin, The Florida Bar  
Dr. Leo Sandon, Florida State University  
Marshall Seiden, Florida Association of Homes for the Aging  
Kelly Skidmore for Senator Ron Klein  
Dr. Alvin Smith, Oncologist, Florida Medical Association  
Dr. Howard Tuch, Florida Health Care Association  
Susan White, Florida Hospital Association

**Advisory Board Members:**

Dr. Lofty Basta  
Dr. John Carnes, Bayfront-St. Anthony Health Care

**Observers in Attendance:**

Bill Allen, Speaker  
Kate Callahan, Pepper Institute on Aging and Public Policy  
Ed Casoria, Speaker  
Cheryl Cummings, Beardall Center Director  
Ann Keller, Paramedic, Bureau of Health, Speaker  
Kim Kruse, Pepper Institute on Aging and Public Policy  
Molly McKinstry, Florida Association of Homes for the Aging  
June L. Noel, Dept. of Elder Affairs  
Dr. Richard Tucker, Host  
Tanya Williams, Board of Medicine

**Staff:**

Dr. Melissa Hardy, Pepper Institute on Aging and Public Policy  
Melanie Meyer, House Committee on Long Term Care

The meeting/forum convened at 10:00 AM. Cheryl Cummings, Beardall Center Director, introduced Dr. Richard Tucker as host/facilitator of the meeting and Dr. Bob Brooks, Chairman of the Panel, who welcomed everyone, introduced those seated at the podium, explained the agenda format, and gave a brief overview of the Panel and its mission.

A presentation on Advance Directives was given by Ed Casoria and Bill Allen. Points reviewed and defined by Mr. Casoria were:

- Statute References (Chapter 765, F.S.)
- Living Will according to Florida Statutes
- Health Care Surrogate
- Do Not Resuscitate Order
- Durable Power of Attorney

Mr. Allen spoke on the following:

Wishes are not carried out at end of life due to:

- A minority of physicians still do not want to stop treatment.
- Documents are often full of ambiguities.
- Social mores, our cultural denial of death, and spiritual beliefs.

Mr. Allen went on to explain:

- Health Care Surrogates
- Durable Power of Attorney documents.
- Creating a Values History (a person's concept of quality of life)

Dr. Brooks opened the Forum by inviting questions/comments from the audience to the Panel.

- Dr. Lofty Basta -- Commented on the fact that advance medical planning has lost its focus; perhaps the focus should be on particular circumstances of the patient such as his/her desire to avoid indignity at the end of life. He voiced concern that documents can become an impediment.
- Chester Damron (Chaplain, FL Hospital-Fish, Orange City): Asked that the Panel speak on the five wishes document. The Panel responded with an explanation.
- Tom Sawyer (Psychologist & Elder Law Attorney) -- Commented on Powers of Attorney and the fact that they usually relate to property along with health care surrogate decisions. He explained the distinction between the two and then encouraged that everyone keep foremost in mind the importance of a person's quality of life.

E. Bentley Lipscomb gave an overview on the differences between Living Wills and DNROs: Living Wills work inside the hospital, while DNROs work outside hospital (EMTs look for this).

- Reggie McGill from Representative Brown's office thanked Panel members for the invitation and for their efforts related to this important issue.

Dr. Brooks asked that everyone make an effort to limit questions to 3-5 minutes in order that everyone be heard. He then introduced the Panel members:

More questions/comments were then taken from the audience.

- (No name given) -- Question: If we have a Living Will, renewed each year, how can we be sure in an emergency that it will be honored since you don't always know the doctor? A personal example was given. A central registry was suggested by Dr. Basta. He related that a Living Will must be very specific and always be honored.

Bill Allen also recommended that a Living Will be specific and that an ethics consult can be requested. He stated that the statute provides for expedited judicial review to quickly get a judge who will hear both sides and determine who is best able to represent a patient's wishes.

Dr. Smith suggested that families make their physician comfortable with end of life decisions other than those which are legally defined.

- A suggestion was made that medical school curriculum should include making physicians comfortable with the fact that death is an acceptable thing. A Panel member responded that education is provided at medical schools and is a required part of the curriculum.
- Sally (last name not clear) -- What is the procedure for a person wishing to donate their body (rather than organs which might not be viable) for medical research? It was advised that medical schools will accommodate those requests and that they be contacted in advance. A Panel member offered that Florida Statutes provide for organ and tissue donation, and when driver's licenses are issued they offer the option.
- (No name given) -- Suggestion was made that a surrogate advise whomever is paying a person's medical bills to refuse to pay for unwanted medical treatment.
- Randy Richards (social worker in a nursing home) -- Since the DNR order calls for only one signature, and the law says two physicians must be consulted, where does the other physician sign? An answer was offered by a Panel member: According to Florida law, two physicians must be consulted. If there is doubt about whether a patient is terminal two physicians' signatures are needed. Although the form calls for only one signature, two physicians consult, and one signs. Several members attempted to answer this question and explain the law.
- (No name given) -- How can one be assured that EMTs will not treat if a Living Will is in effect, but terminal issues are not the case. Answer offered: Refusal of treatment form is an alternative, however, the physician must be aware of it, and the person must not call EMTs.
- (Student at UCF) -- Commented that the signature is lacking for a second physician on DNRO form. A Panel member explained that the form is accepted with one signature in Orange County in a pre-hospital environment.
- M.J. Mahoney (Paramedic Chief) -- Explained his position as being difficult and a great responsibility. He urged everyone to be in compliance by having documents readily accessible. He commented that working on patients that have arrested is

difficult for EMTs, since they realize that they perhaps may not be effective in their treatment.

- Judy Gaines (Personal Alternatives, Inc.) -- Offered the following: a dying person often experiences a sense of guilt due to burdening their family, and that in dealing with it one must simplify the process whereby people can have their wishes carried out; cost of care can be a factor in dealing with this issue; respect for the person should be a key factor in determinations/decisions; quality of life should be emphasized rather than cost of care; but, cost of care in some cases can be a factor if the person involved makes that decision.
- Bill Hasenyager (retired chaplain, counselor) -- 30 years ago it was easier, today physicians have their hands full in respecting patients' wishes. He suggested that a hospital chaplain be added to the Panel.
- Lori Johnson (DOEA, CARES unit) -- Presented a real-life situation whereby a patient called on EMTs for seemingly inappropriate tasks such as pet care. A Panel member explained that when a person is competent, their wishes should be respected; however, this particular issue should be further addressed.
- (SHINE member) -- Recommended that a vial be used to hold all medical information, a dot be placed on your door indicating information location for EMTs (i.e., go to refrigerator for information), and information location should be made clear. It was also suggested that medical information & personal wishes be printed on a card and kept on your person at all times. The creation of a central registry was mentioned again.
- Polly Stevens (volunteer for SHINE & Sheriff's Dept.) -- Suggestions included "Citizens at Risk" program, and Vial of Life (contains medical information and Living Will or DNRO documentation).
- Cathy Lieblich (Winter Park Health Foundation) -- Recommended a great need for education on exactly how to make informed decisions with advance directives. She indicated a poster in the back of the room for review.
- Lori Daiello (Care Link Management) -- Expressed a concern related to undue pressure on families to insert feeding tubes, especially in nursing homes.
- Bob Green (nursing home administrator) -- Suggested looking at advance directives related to finding someone to make treatment decisions for those with no families available. A committee of proxies was suggested for when families cannot be found or will not take interest and refuse to make decisions. An opinion was submitted that the problem is related to the type of society we live in. It was suggested that District Courts could become involved and appointed guardians could be the answer but that much training would be needed.
- Carol Waters (memory disorder clinic in Melbourne) -- Spoke about the "Guardian System."

- (No name given) -- A concern was voiced regarding a lack of palliative care and what was being done about it. The Hospice concept was offered by a Panel member.
- (No name given) -- A question was posed regarding pain management and was then explained by a Panel member. The Florida Commission on Pain Management was offered as an informational source.
- (Medical social worker) -- Offered a charge to the Panel: To provide education of advance directives to all sectors of our society - cross educational & age barriers. Suggested were universal practices for advance directives with a clarifying approach from all health care fields, and adding an ethics committee as an additional choice to families.
- Rosa Sullivan (professional guardian) -- Offered that estate and guardianship services are available and gave a brief overview.
- (No name given) -- A question was raised regarding changes to Living Wills such as cremation. A Panel member responded that changes can be made to a Living Will at any time.

Dr. Smith encouraged all to offer comments on possible formats for how to proceed with further work on the Panel's issues.

At 1:00 PM, Dr. Brooks thanked the Forum participants and announced a lunch break, after which Panel Workgroups would convene their respective meetings.

At 3:08 PM, the full Panel reconvened and Dr. Brooks provided an update including further information on the following future meeting date schedules:

- Monday, October 26 in Miami: Meeting will begin at 11:00 AM instead of 10:00 AM. A schedule and map will be provided as soon as possible.
- Monday, October 26 in Ft. Lauderdale: 5:00 PM.
- Tuesday, October 27 in W. Palm Beach: Meeting will be held from 10:00 AM until 1:00 PM instead of 9:30 AM to 12:30 PM.

Dr. Brooks asked for time frames needed by workgroups and instructed that they must notice any scheduled conference calls and provide minutes from them. The need for distinct definable issues was reiterated. The Panel was reminded that research data or information needs should be directed to Melissa Hardy or Melanie Meyer.

Facilitators of Workgroups gave the following reports:

Advance Directives Workgroup - Kate Callahan related that the group would like to request that the meeting minutes from the morning reflect that the comments by EMT personnel were not made by a Panel member and that they did not denote the Panel's opinion. Key points expressed include: a need to compile frequently asked questions and problems regarding advance directives from hospitals, EMTs, and nursing homes; that the statute language be made easier to understand; a need to collect more data on

which to base the Workgroup's recommendations; the problem of litigation between physicians and family members; a possible penalty for not following wishes; conflict/dispute resolution; and a method by which the Panel can prioritize what they need to look at. Four major priorities include:

1. Litigation
2. Education (or lack of)
3. Communication
4. Political mobilization

Pain Management Workgroup - Dr. Tuch presented the Workgroup's key points, which included: palliative care issues & pain management; the fundamental need for education in multiple areas regarding pain management; how to focus on professional groups for education - perhaps making a component of that education mandatory; a need to encourage cultural change; how organizations can be encouraged to implement changes regarding pain management; encourage use of different kinds of educational tools; educational needs for the general public; promote a sense of what is acceptable in pain management; education and measurement of outcomes including financial barriers to measurement; development of specialty services in medical school to focus on new area of medicine as a way to gain attention to need; patient care needs to be a part of provider approach; access to effective patient care is a concern both inside and outside Hospice; Medicaid policies regarding medication allocation is a problem.

Financial/Regulatory Issues Workgroup - LuMarie Polivka-West reviewed the Workgroup's key points, which included: involving communities / neighborhoods in education regarding advance directives; identifying systems of measurement of end-of-life care being provided; recognizing that as a committee we should recommend the requirement of mandatory advance directives training for all providers of care; identifying rules / laws governing end-of-life care (by AHCA); and realizing the protocol for choices in end-of-life care.

A suggestion was made that a Hotline for palliative care (311?) could be a possibility and an alternative to the 911 emergency call.

It was recommended that the Panel focus not only on what we do know but also what we do not know to promote the development of research on our topic.

In an effort to identify problems related to end-of-life care, a survey of all healthcare providers was discussed. Marshall Kelley offered to construct the survey and work with input from others to compile the content.

Dr. Brooks encouraged Panel members to bring in experts to address workgroups. He further suggested that alternates be sent to meetings members cannot attend and to alert his office and identify the alternate so pertinent information can be forwarded to them.

Time frames were discussed. The Preliminary Report is due January 31, 1999 and should include any aspects that would require legislative changes during Session. The probability of convening one meeting in January was mentioned, where a day is spent working with specific issues. A meeting in early December should have a specific bullet-

point list of concerns and solutions so Panel members have an opportunity to vote on workgroup issues before January.

The meeting was adjourned at 4:00 PM.

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**Monday, October 26, 1998**  
**Steven Clark Building, 111 NW 1<sup>st</sup> Street Miami, FL**

**Panel Members in Attendance:**

Representative Dr. Bob Brooks, Florida House of Representatives  
Joan Fulbright, Association of Community Hospitals and Health Systems  
Stan Godleski, Consumer Advocate  
Jack Gordon, Hospice Foundation of America  
Marshall Kelley, Agency for Health Care Administration  
Dr. Georgie C. Labadie for Cathy Emmett, Florida Nurses Association  
Mary Labyak, Hospice of Florida Suncoast  
David B. Levine for Dr. Robert Panzer, Florida Board of Osteopathic Medicine  
E. Bentley Lipscomb, Department of Elder Affairs  
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Kenneth S. Rubin, The Florida Bar  
Kelly Skidmore for Senator Ron Klein  
Dr. Alvin E. Smith, Oncologist, Florida Medical Association  
Jim Towey, Commission on Aging with Dignity  
Dr. Howard Tuch, Florida Health Care Association  
Dr. Susan V. White, Florida Hospital Association  
Tanya Williams for Dr. Gary Winchester, Florida Board of Medicine

**Advisory Board Members:**

Rev. Celillon Alteme, Tampa General Healthcare  
Dr. Kenneth W. Goodman, Forum for Bioethics and Philosophy  
Jane E. Hendricks, Attorney at Law  
Rev. Marilyn Mayse, University Medical Center  
Dr. D. Mike McCarron, Florida Catholic Conference  
Freida Travis, Department of Health Bureau of Emergency Medical Services  
Henry Pearson, Pearson's Rest Home

Dr. Melissa A. Hardy, Pepper Institute on Aging

The meeting was called to order at 10:00 AM by Chairman Dr. Bob Brooks. Panel members, Alternates, and Advisory Board Members introduced themselves to the audience.

Questions/comments were taken from the audience.

- Kelly Rice Schild, Vice-president for a Miami nursing center –  
She raised a concern that nursing home decisions are based on the fear of liability. Her facility was given a citation with two deficiencies in response to the non-transfer of a patient to the hospital. But, the facility was complying with the Durable Power of Attorney, which met the Patient Self Determination Act of 1991, but did not 'fit' Florida Law.



- Arthur Berger, Commissioner for the City of Aventura – raised a concern that the blind rely solely on the Library of Congress’ free audio books, and there are no audio books on Advance Directives. Pointed out the issue of access to these materials for special populations. The Florida Bureau of Blind Services has provided an audio tape for Floridians who are blind, but Mr. Berger pointed out the need for material at the national level and for blind residents of other states. A Panel member commented that there is also a need for materials for the hearing impaired. A second Panel member expressed concern about the lack of consistency across state lines, and the public’s fear that their end of life wishes won’t be honored if they are traveling in another state.
- Ariella Rodriguez, Health and Social Services for Little Havana (serve 39,000/yr) – Addressed the needs of the Hispanic population in Miami, and reminded the Panel that Hispanics make up over 55% of the population of south Florida. Her concern is how to reach and get information out to Hispanics, since many end of life topics are considered ‘taboo’ and there are cultural barriers to discussing these issues. For example, Hispanics are not likely to use Hospice because of the taboo about not speaking about death and terminal situations. Expressed that we need a well-thought out culturally competent public education campaign, its not a simple translation issues. A Panel member reiterated these differences and expressed his hope that the Panel will take these cultural and racial differences into account.
- Dr. Andrew Eagle, Medical Director of Critical Care at Baptist Hospital in Miami – Discussed the increasing trend of family surrogates who insist/demand futile life support, the proliferation of chronic care and subacute care facilities for the care of ventilator patients and patients in vegetative states. He pointed out that the Futility Guidelines developed by the Health Council of South Florida should be consulted, and suggested that the Legislature address the issue of whether patients and families have the “right” to demand futile care. He stresses the role of hospital Ethics Committees in the end-of-life care process.
- Chris Myles, Miami/Dade Fire Department – He commented on the aggressive nature of the EMTs life support policy, and the 401 requirement that EMTs take aggressive action. He expressed that paramedics would like the authority to respond to end-of-life DNR orders with the same absence of liability that Hospice nurses have. This would require an amendment to Ch. 401 to allow paramedics to cease care. A Panel member asked if Mr. Myles knew of cases where the valid DNR form was not followed because the family was there. Mr. Myles responded he did know of cases like that.

At 12:50 Dr. Brooks thanked the participants and announced a lunch break, after which the Panel Workgroups are to conduct their respective meetings. Dr. Brooks asked the Workgroups to begin prioritizing their top issues.

#### Financial/Regulatory Issues Workgroup

The group summarized its progress: the group has laid out the continuum of care, identified relevant actors (facilities, health care providers, etc.), and for each domain identified gaps and the legal/regulatory barriers (i.e. different forms for advance directives, financing inequities such as the lack of case mix for hospice), and now we

need to identify areas that we want to make recommendations on (i.e. financing, education).

Areas that the group identified as concerns include:

- the education of doctors and the public about end of life care is a primary concern
- the issue of how to change the training of physicians and health care providers; whether or not to make education in end of life care mandatory, and whether this would increase participation; how to ensure that people attend training and take learning the material seriously
- the need for different levels of training depending on type of physician or health care professional
- removing the barriers to increased use of hospice in nursing homes
- addressing the gap in funding between state law (last year of life) and Medicaid and Medicare (last 6 months), and the need for multiple levels of reimbursement
- the need for demonstration projects to try alternative funding and eligibility criteria
- concern over placement decisions and transfer of patients, readmittance, etc.
- the need to develop a measure of the quality of end of life care and a 'good' death (dying where they wanted to and with minimal pain)
- the need for a commitment to the discussion of end of life care at the beginning of the treatment process (during admissions, for example)

Group leader LuMarie Polivka-West handed out the Attorney General of New York's Commission on Quality Care at the End of Life Final Report, 1998.

Before the next meeting, each member of the group was encouraged to describe in writing the barriers to end of life care within their particular arena.

#### Advance Directives Workgroup

Group leader: Stan Godleski substituting for Kate Callahan

Participants: Stan Godleski, Kenneth S. Rubin, Susan V. White, Ph.D., Belita Moreton, Jack Gordon, Frieda Travis, Jim Towey, Jane Hendricks, Henry Pearson, Barbara Janosko, Leena Nehru, Celillon Alteme, Marilyn Mayse

Welcome and Introductions: Stan Godleski welcomed the workgroup members and guests on behalf of Kate Callahan as she was unable to attend the meeting. Each participant was introduced.

Legislative Mission: Stan reviewed our mission as defined in the legislation and asked for comments on how to prioritize issues to address the directive. The priorities should be based on our previous discussions of issues and input from testimony by the public.

Mission: The current use of advance directives, to determine whether changes are necessary to ensure that, once prepared, advance directives will be honored in any health care setting.

Priorities: Mr. Rubin identified the following priorities for the workgroup:

- DNRO
  - Definition of terminal and the need for a terminal diagnosis
  - The need for two physicians to verify terminal status

Dr. White concurred that these three areas seemed to be the most problematic or contentious issues for patients and the public in getting advance directives honored. These three areas would require legislative change.

Mr. Gordon inquired as to what the legislation would say and the response was that we needed to first agree on the issues, then we could obtain additional expertise and input in drafting revised legislation.

Mr. Towey suggested that a draft be developed before presenting to others so that the particular focus would not be lost with a myriad of other issues related to end of life care. Comments from a representative indicated that AHCA had conducted a survey of the public and the findings indicate similar concerns that we have listed in our priorities. These issues continue to emphasize a focus on self-determination through the use of advance directives and living wills but an inability to have wishes maintained due to the barriers of:

- Pre-hospital care requiring DNRO for terminal condition
- Not honoring the wishes expressed in living wills
- Difficulty getting support in hospital for DNR and honoring living will
- Multiple forms for different settings without continuous access to forms

Other items that were raised for discussion included:

- F.S. 765 and 401 - How do they fit? What was the origin? How was the decision made for two physicians?
- EMS has concerns that the public does not understand the differences between advanced directives and DNRO.
- The issues stem from differences in prehospital and hospital forms, use of DNRO, and honoring living wills.
- There is a need for simplification with forms and processes.
- Immunity is needed for EMS and other caregivers.

Summary: The workgroup will focus on the following areas:

- Integration of F.S. 765 and 401 into a meaningful statute.
- The definition of "terminal" and the associated need for two physicians to attest to the condition is an unworkable burden and a conflict with self-determination and needs revision.
- Self-determination and the valid refusal of treatment need to be addressed as they are not incorporated into the current statute sufficiently.
- There is a need to build in immunity, where appropriate, for EMS workers and other caregivers when applying DNRO and advance directives.

Handouts: "Perceptions by family members of the dying experience of older and seriously ill patients"; "Do advance directives provide instructions that direct care?"; "Advance directives for seriously ill hospitalized patients: Effectiveness and the patient self-determination act and the SUPPORT intervention"; Florida Hospices Inc.- Member survey results of most common concerns/complaints expressed on advance directives.

### Pain Management Workgroup

Group leader: Howard Tuch reiterated the workgroup's focus, to improve and enhance pain management and care. It was the consensus of the workgroup to focus on educational efforts.

Identified points of concern include:

- the need to focus on educational for physicians and health care practitioners
- the possibility of developing a directory of resources and a Helpline for last minute physician references regarding medications

- it was pointed out that many specialty boards are including pain management in Board exams, and it was suggested that we need to keep incentivizing education instead of mandating it
- the need to educate the public directly to increase their awareness of pain management so that they can ask questions and demand better care
- the need for more research on palliative care in the home and in nursing homes since people are not receiving adequate pain management
- the importance of access to medications, and the difficulty of getting narcotics at night from a pharmacy
- the need to prevent pain in addition to providing care in reaction to pain
- the need for societal change so it becomes socially unacceptable for a patient to remain in pain

At 2:25 the full Panel reconvened and Dr. Brooks reminded everyone of the public testimony to be held at Tamarac City Hall at 5:30. The importance of compliance with Florida's Sunshine laws was reiterated to Panel members. Dr. Brooks presented an update of the next meetings in November:

- Monday, November 9th in Sarasota: Public testimony will be taken from 10 am to 12:30. After lunch members will travel to St. Petersburg for a meeting of the Working groups from 3:00 PM to 4:30 PM, and then public testimony will be taken from 5:00 to 7:30pm.
- Tuesday, November 10<sup>th</sup> the Panel will take testimony in Zephyrhills from 10:00 am until noon, and then adjourn around 1:00 after wrapping up.

Preliminary plans for the December 4<sup>th</sup> meeting in Jacksonville were discussed. Dr. Brooks suggested taking public testimony from 10:00 am until noon, having a working lunch among the Working groups from 12:00 – 1:00, and then reconvening as a full Panel for a work session from 1:30 until 4:30. Secretary Lipscomb said that the Mary Singleton Senior Center in Jacksonville would be willing to host the meeting at their facility.

The date for the January meeting has not been set at this time.

Facilitators of the Workgroups gave reports of their progress.

Secretary Lipscomb gave the Panel members a copy of a summary of DOEA sponsored workshops on Advance Directives held around the state.

Stan Godlesky expressed a final concern regarding the definition of terminal. His concern was how to integrate 401 with Statute 765 into a meaningful statute, and how to provide immunity when appropriate.

The meeting was adjourned at 3:00 PM.

**Minutes of The Panel for the Study of End-of-Life Care**  
**Monday, October 26, 1998**  
**Public Forum**  
**Tamarac City Hall, 7525 NW 88<sup>th</sup> Avenue, Tamarac, FL**

**Panel Members in Attendance:**

Representative Dr. Bob Brooks, Florida House of Representatives  
Joan Fulbright, Association of Community Hospitals and Health Systems  
Stan Godleski, Consumer Advocate  
Jack Gordon, Hospice Foundation of America\*\*\*  
Marshall Kelley, Agency for Health Care Administration  
Dr. Georgie C. Labadie for Cathy Emmett, Florida Nurses Association  
Mary Labyak, Hospice of Florida Suncoast  
David B. Levine for Dr. Robert Panzer, Florida Board of Osteopathic Medicine  
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Molly McKinstry for Marshall Seiden, Florida Association of Homes for the Aging  
Kenneth S. Rubin, The Florida Bar  
Kelly Skidmore for Senator Ron Klein  
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Jim Towey, Commission on Aging with Dignity\*\*\*  
Dr. Susan V. White, Florida Hospital Association  
Tanya Williams for Dr. Gary Winchester, Florida Board of Medicine

- (name not clear) – commented on the high cost of medications and raised the need for more control over drug prices.
- Joan Hinden , Older Women’s League of South Florida (OWL) – Raised concerns that the wishes of critical patients with living wills are being ignored, the need for a new living will with more specific situational instructions, and about the failure of physicians to treat pain. A Panel asked for a write-up of the experiences of individual members of OWL.
- Shirley Blumfeld, Hospice volunteer who helped establish Hospice in Israel – Pointed out that the yellow DNR sheet doesn’t help and the Five Wishes document is ignored. Commented that it is difficult to get families to talk about wishes for end of life care. Family members sometimes disregard the living will and follow doctor’s suggestions to keep the patient alive - its a matter of educating people otherwise. A Panel member responded to the audience that it is important for families to talk and come to a consensus because it is more likely that wishes won’t be carried out if there is dissention.
- Abe Solsky, City Commissioner in Coconut Creek – Commented on the need for a clear definition of long term care, an open discussion of where LTC can best be provided, an assessment of the role of caregivers, the need to take a close look at isolation and loneliness and how it is linked to LTC, and the need for standardization of home health services.

- Dr. Ann Rubin – Presented her experience, her husband’s surrogate power and living will were ignored because two doctors couldn’t agree that his condition was terminal. Stated that we need to clarify “terminal” because it is not consistent across physicians.
- Bernie Grossman – spoke to represent her husband who died a horrible, rather than a peaceful death. He had a living will but she was told at University Hospital that the living will was worthless. A Panel member expressed the need to educate the public about the limitations of living wills.
- Denise Eikenbloch, Director of the Critical Care Unit at University Hospital – Reiterated the problem with the definition of “terminal” and identified the need for education for hospital staff and community regarding what is terminal, and better communication with families – families don’t realize that living wills do not come into effect until the person is terminal, and doctors won’t identify someone as terminal until the condition is irreversible.
- Dr. David McGrew pointed out that it is unethical to allow patients to suffer and then make them decide if they want emergency life sustaining treatment such as respiration when they are in such pain – this is an educational issue because the public does not know what treatments are available to help ease their pain and what they should expect.
- Larry Mishkin, Vice-mayor of Tamarac – commented that he had a living will prepared by an attorney, but when he was hospitalized he realized that there were circumstances when the living will wasn’t on record, such as in an ambulance, and at another hospital.
- Senator Walter Campbell – commented that this isn’t just a geriatric issue, but a people issue, citing the Perlmutter case. The law is not currently developed enough to deal with these complexities. Pointed out that is essential to have a good doctor/patient relationship to work through the complexities that arise at the end of life, and that the best situation is when the family has the situation worked out.
- Dr. Harmon Weiss – Pointed to the failure of medical schools to teach care of the elderly, end of life care, and death and dying. These are issues that we should start to think about when we are young.
- Ruth Forbes, State Legislative Committee of AARP – Expressed concern that living wills aren’t being honored and would like to see legislation in this area. She offered AARP’s help.
- Representative Greenstein – Commented that living wills need to be clear, transportable and made easily verifiable in many settings. He suggested putting advance directives on a Smartcard to make them easily available.
- Joe Wheeler – Presented the experiences he has faced while caring for his 100 year old mother, and challenged the Panel to fix the problems surrounding end of life care.

- Scott Cole, Registered Nurse and therapist, and owner of assisted living facility – Commented that advance directives have come a long way and have made great progress in the past 10 years. More people know what living wills are, etc. He feels that living wills are followed for the most part. He expressed concern that regulatory laws do not allow for aging in place, since the law (even under Hospice) requires that the person be able to self-evacuate, or have 24 hour care, in order to remain in the assisted living facility. He suggested that this needs to be changed, especially in fire sprinklered facilities, otherwise people are forced out of the facility into nursing homes which have different regulations but are not any safer.

At 7:35 PM Dr. Brooks thanked the Forum participants and adjourned the meeting until tomorrow morning in West Palm Beach at 10:00 AM.

**Minutes of The Panel for the Study of End-of-Life Care**  
**Tuesday, October 27, 1998**  
**Public Forum**  
**Jewish Family Services, 4605 Community Drive, West Palm Beach, FL**

**Panel Members in Attendance:**

The Honorable Dr. Bob Brooks, Florida House of Representatives  
Joan T. Fulbright, Association of Community Hospitals and Health Systems  
Stan Godleski, Consumer Advocate  
Marshall E. Kelley, Agency for Health Care Administration  
The Honorable Ron Klein, Florida Senate  
Mary Labyak, Hospice of Florida Suncoast  
E. Bentley Lipscomb, Department of Elder Affairs  
Belita Moreton, Florida League of Health Systems  
LuMarie Polivka-West, Florida Health Care Association  
Molly McKinstry for Marshall Seiden, Florida Association of Homes for the Aging  
Kenneth S. Rubin, The Florida Bar  
Dr. Alvin E. Smith, Oncologist, Florida Medical Association  
Dr. Gary Winchester, Florida Board of Medicine

The meeting began at 10:09 AM with a welcome by Dr. Brooks and an invitation for questions/comments from the audience.

- Pat Mackley – Discussed her mother’s care in the hospital and with Hospice and raised concerns about hospitals and physicians honoring living wills and providing comfort care. Expressed her concern about families who think the paperwork is in order for care of their loved ones, and it is very painful to find out things aren’t in order and final wishes are not honored. Suggested that frail persons entering the hospital with a living will in place be given a different color ID bracelet for easy identification.
  
- John Silver, RN, Critical care – Raised four points that need addressing for better end of life care. The first is the need for the restructuring of the health care system (the system is archaic and Hospice is underutilized) to make it more sensitive to individual needs. Second, he raised concern over the lack of pain management and that physicians are overly concerned about the regulation of narcotics. Problems with living wills need to be addressed. He commented that nurses are receptive to living wills, but that a lot of decisions are not within their control. Fourth, as a society we need to come to terms with dying and need more public discussions. Panel members also voiced their concerns about pain management. Dr. Smith expressed his frustration over the continued concern over writing pain prescriptions. Stated that for seven years there have been no sanctions for over prescribing, but that the problem is one of misunderstanding, misperception, and lack of knowledge. Dr. Winchester reiterated the lack of understanding about narcotics among physicians and felt that this starts in medical school. Suggested the model guidelines for the treatment of pain that is part of the EPEC project as a resource.
  
- Dr. Robin Fiore, Medical ethicist at Florida Atlantic University – Discussed her research on ethics committees. She found them to be a powerful, but underutilized



force with the potential to bridge the gap between doctors, patients and families. She expressed the need for a systematic educational initiative to train ethics committee members, and that this requires the establishment of a budget for education, which most institutions don't have. She suggested that HCFA may be able to help with this. She also suggested that nursing home ethics committees should be given legal protection. One Panel member commented that ethics committees should be marketed to the public so that they are aware of this resource. Another Panel member suggested that the Florida Bar help to serve as ethics educators.

- Ken Goodman, ethicist, University of Miami – Explained the efforts of the University of Miami's medical school to increase training in end of life care. He expressed support for the role of the ethicist, and concern that standards are too low for the educational requirements for ethics.

At 1:00 PM Secretary Lipscomb provided closing comments and thanked the audience for their participation (Dr. Brooks needed to leave the meeting early). The meeting was adjourned.

**Minutes of The Panel for the Study of End-of-Life Care  
Monday, November 9, 1998  
Sudokoff Hall, University of South Florida Sarasota, FL**

**Panel Members in Attendance:**

Representative Dr. Bob Brooks, Florida House of Representatives  
Cathy Emmett, Florida Nurses Association  
Mary Alice Ferrell for Kenneth S. Rubin, The Florida Bar  
Stan Godleski, Consumer Advocate  
Marshall Kelley, Agency for Health Care Administration  
Senator Ron Klein, Florida Senate  
Mary Labyak, Hospice of Florida Suncoast  
E. Bentley Lipscomb, Department of Elder Affairs  
Linda McGrath for Belita Moreton, Florida League of Health Systems  
June Noel, Department of Elder Affairs  
LuMarie Polivka-West, Florida Health Care Association  
Marshall Seiden, Florida Association of Homes for the Aging  
Dr. Alvin E. Smith, Oncologist, Florida Medical Association  
Jackie Roberts for Jim Towey, Commission on Aging with Dignity  
Dr. Susan V. White, Florida Hospital Association  
Dr. Gary Winchester, Florida Board of Medicine

**Advisory Board Members:**

Rev. Celillon Altame, Tampa General Healthcare  
Kate Callahan, Huntington Research Group  
Dr. David M. McGrew, American Academy of Hospice and Pain Medicine  
Henry Pearson, Pearson's Rest Home  
Freida Travis, Department of Health Bureau of Emergency Medical Services

Dr. Melissa A. Hardy, Pepper Institute on Aging and Public Policy  
Melanie Meyer, House Committee on Aging and Long Term Care

The meeting was called to order at 10:10 a.m. by Chairman Dr. Bob Brooks. Panel members, Alternates, and Advisory Board Members introduced themselves to the audience.

Public Testimony: questions/comments were taken from the audience.

↳ Ruth Woodrow – “Do not resuscitate orders” (hereafter DNR or DNRO) requires terminal diagnosis, even though less than 47% of CPR is successful with the elderly (in Nursing Homes). Concerned that it is difficult to get a terminal diagnosis even for very ill patients. Ms. Woodrow explained a case of a doctor who finally discontinued treatment for an elderly gentleman who died in five (5) hours even though he wasn't “terminal.” Ms. Woodrow then made the following suggestions:

1. Broaden application of Advance Directives (hereafter AD) beyond terminal: severe, irreversible illnesses, disabilities
2. Educate physicians about care success and risk of CPR on elderly.

3. Educate public on the right to refuse treatment; what to do when wishes of patient are not honored.
4. What about people who have no advocates?

From the panel, Dr. Smith responded that the patient does not have to be terminal for the patient or surrogate to refuse treatment.

- ☞ Kathy Griffin, Social Worker – Ms. Griffin stated that AD responsibilities fall to social workers. Ms. Griffin is very involved with End-of-Life (hereafter EOL) care and documentation, and said that there is confusion over necessity of “terminal” for DNRO. Noticed that two (2) DNR forms differ where one says “terminal” and the other does not.

From the board, Frieda Travis responded and said that form without “terminal” still required treatment in keeping with Statute 765. Attorneys later made the terminal diagnoses “explicit” on the form.

- ☞ Ira Wiesner – A facility-based DNR does not have “terminal” requirement.
- ☞ David Tannenbaum – Mr. Tannenbaum commented that he is hearing bureaucratic haggling. He and his wife have companion Living Wills (hereafter LW) and want DNRO if the likelihood is that they would persist in a vegetative state. From the panel, Dr. Brooks responded and said that DNRO in the home requires “yellow” form and requires “terminal.” More leeway in hospitals than in community. From the panel, Mr. Lipscomb responded and said that the reason for the EOL panel is to deal with confusion. Raised the question of whether ALF qualifies as a health-care facility, rather than a custodial facility. From the panel, Ms. Ferrell responded and said that standard procedure is applied differently depending on the site [facility].
- ☞ Kathy Griffin, Social Worker – Ms. Griffin stated that there are many people who want all possible treatment, and that health-care providers and others can be judgmental. States that often we assume the patients wouldn’t want to live “that way,” and thinks that we’re too ready to accept statements of wanting to die as a real request or desire. Advises that we protect those who want to live as we protect the rights of those who really want to refuse treatment.
- ☞ Jean Hendry – Talked about pain management. Ms. Hendry said that she would not want extensive pain management, because it wouldn’t be good. She also states that the sacredness of life is a religious concept and not part of law. Ms. Hendry said that the government has no business interfering with an individual’s decision to die. From the panel, Sen. Klein responded and asked what society’s involvement in these practices should be. Said that there are many different scenarios.
- ☞ Dick Kerckhoff, Hemlock Society – Mr. Kerckhoff is a former professor at Purdue University in Family Development; attended a conference in Switzerland on a right-to-die program. Mr. Kerckhoff said that palliative care should not be used as an excuse to refuse the patient’s wish to die.

- ☞ Dr. Jack Tarzeki – Dr. Tarzeki looked at the competency issues and sees a dilemma: determining surrogate competence. Said that you cannot assess competence of the surrogate, because the surrogate is not a patient. Also, said that there is a reluctance to move a patient to terminal status, because they lose benefits or have services reduced. Counseling by psychologists is not allowed if [the patient is] terminal. Cited the need for separate EOL care for those who are under the age of 18 (< 18) and for those over the age of 18 (> 18). Also cited the case of those in state custody, and asked who is the surrogate, who is the guardian The following were then discussed: children experience pain also, health insurance providers being part of policy (terminal illness blocks benefits), Medicare, reimbursement issue.  
From the panel, Ms. Labyak responded that Hospice does have children’s care and a specialized children’s hospice benefit. She also pointed out that the view that a demented person cannot benefit from counseling is problematic.  
From the board, Dr. McGrew responded that perhaps Hospice provides care and does not want to reimburse Dr. Tarzeki in his case for counseling. He also pointed out the distinction between reduction in services and shift in service provider.
- ☞ Dr. Greg T. Dickenson – Dr. Dickenson commented that the ethics committee at hospitals are the stumbling blocks to AD, because of the need to designate patients as “terminal.” (no trigger) He thinks that we should just follow the wishes of the patient/families.  
From the panel, Senator Klein responded and wanted to clarify how it works.  
From the panel, Dr. Brooks responded and said that there is a danger there and that there is a need for protection.
- ☞ Margaret Chamerall – Ms. Chamerall would like to have option of assisted suicide. Said that there is lots of wording and not much underlying philosophy in the area of assisted suicide and that the U.S. is more concerned with preserving life. Mentioned also that the Eastern European philosophy is more accepting of death.
- ☞ Paul Fishman, physician – Mr. Fishman mentioned that not just pain management should be looked at but Alzheimer’s, as well.  
From the panel, Dr. Brooks responded that he doubts that kind of major legislative change would come out of the Panel and that it wasn’t included in its charge.
- ☞ Dr. Mark Magenheim, Hospice – Dr. Magenheim commented that we should consider pain as a 5<sup>th</sup> vital sign along with temperature, blood pressure, pulse, and respiration. Said that we should make it part of routine clinical practice.

The Panel then adjourned to travel to St. Petersburg.

**Minutes of The Panel for the Study of End-of-Life Care**  
**Monday, November 9, 1998**  
**Sunshine Senior Center St. Petersburg, FL**

**Panel Members in Attendance:**

Samira Beckwith, Hospice  
Representative Dr. Bob Brooks, Florida House of Representatives  
Dr. Marie E. Cowart, Pepper Institute on Aging and Public Policy  
Cathy Emmett, Florida Nurses Association  
Mary Alice Ferrell for Kenneth S. Rubin, The Florida Bar  
Stan Godleski, Consumer Advocate  
Marshall Kelley, Agency for Health Care Administration  
Senator Ron Klein, Florida Senate  
Mary Labyak, Hospice of Florida Suncoast  
E. Bentley Lipscomb, Department of Elder Affairs  
Linda McGrath for Belita Moreton, Florida League of Health Systems  
June Noel, Department of Elder Affairs  
LuMarie Polivka-West, Florida Health Care Association  
Marshall Seiden, Florida Association of Homes for the Aging  
Dr. Alvin E. Smith, Oncologist, Florida Medical Association  
Dr. Susan V. White, Florida Hospital Association  
Bill Bell, Florida Hospital Association  
Dr. Gary Winchester, Florida Board of Medicine

**Advisory Board Members:**

Rev. Celillon Alteme, Tampa General Healthcare  
Kate Callahan, Huntington Research Group  
Jane E. Hendricks  
Rev. Marilyn Mayse  
Dr. David M. McGrew, American Academy of Hospice and Pain Medicine  
Henry Pearson, Pearson's Rest Home  
Freida Travis, Department of Health Bureau of Emergency Medical Services

Dr. Melissa A. Hardy, Pepper Institute on Aging and Public Policy  
Melanie Meyer, House Committee on Aging and Long Term Care

The meeting was reconvened at 5:30 p.m. by Chairman Dr. Bob Brooks. Panel members, Alternates, and Advisory Board Members introduced themselves to the audience.

Public Testimony: questions/comments were taken from the audience.

↳ Dawn Cole – Ms. Cole spoke of a personal experience showing the other side of the coin. A doctor put “no code” on her mother’s chart. Ms. Cole is wondering if this will follow her mother the next time she is in the hospital. She also wanted to know why a doctor can do this?

From the panel, Dr. Smith responded and said that a physician has no positive duty to treat but a physician has a positive duty to inform.

From the panel, Mr. Kelley responded and said that people in this situation should have a meeting with hospital administration to make wishes clear and expectations about next admission.

From the panel, Mr. Lipscomb responded and said that people in this situation should put their wishes in writing and give a copy to the doctor and then to the hospital.

- ☞ George Pitcher – Mr. Pitcher talked about his wife’s death as a result of poor nursing home care. His wife was transferred four (4) times and neglected.
- ☞ Manuel Fernandez, Hemlock Society Member – Mr. Fernandez would like to see patients given the right to refuse treatment. He suggests that a representative from a right to die organization look into this. Talked about how it took a lot of effort to get the Living Will legislation passed.
- ☞ Gerry Moyer, Hospice – Mr. Moyer spoke about Hospice care helping people. Asked if people have the right to choose type of care. Said that Hospice is also there to help the family members. Told a story of a daughter who was angry, because she thought her mother was giving up, but that wasn’t true. Hospice explained to the daughter that the mother was living in a nursing home for a reason. Have Hospice care in nursing homes.
- ☞ Martha Lenderman, Hospice of Florida Suncoast – Regulatory and financial problems were pointed out by Ms. Lenderman, also internal and external scrutiny taken. Commented on ethics committee: look at all components of care, external scrutiny focuses on a few terminally ill patients who live too long. Physicians are afraid that they’ll refer someone “too soon,” and this diverts resources from client care to charitable care. Has suspicion of charitable care. Chapter 400 requires Hospice to serve terminally ill people. There is a plan to provide uncompensated care. There is fear that it will be perceived as an illegal inducement by the federal government. Which may look at a few measures and assume that providing “free” care now is to induce use of compensated services later. Florida licensure law requires care be given. Recognize role of Hospice in general community.  
From the panel: Dr. Brooks responded and said that he recently toured Hospices and wanted to know if Ms. Lenderman believed that issues of audits were related to federal or state.  
Ms. Lenderman responded and said that the burden is at federal level. The state supports charitable care. The average length of service dropped from 55 to 23 days. Then moved service up to 29 days. Clearly this is a denial of care, and the federal government was more threatening a year ago, but it has not been dropped. The pressure is off but the feel is temporary.  
From the panel, Ms. Beckwith responded and said that MDs are concerned that patients won’t die within 6 months. 39% die within 2 weeks of admission. Asked why are people getting Hospice care so late.  
From the panel, Mr. Lipscomb responded and said that outcome measures are designed for acute care.  
From the panel, Dr. Smith responded and said that palliative care is being developed and some Hospices don’t pay for chemotherapy or radiation. The detriment to referring to Hospice is that physicians didn’t like giving up relationships with the patients. Asked if Hospice would allow primary care physicians involvement/compensation.

From the panel, Dr. Brooks responded and said that there are certain policies related to reimbursement issues that interfere with providing best care.

- ↳ Bee O'Malley – Ms. O'Malley asked for there to be decisions made and a plan made that takes a burden from the patients.
- ↳ Becky McDonald, Hospice administrator – Ms. McDonald spoke on a few topics: education in EOL care, EOL training required for nurses in Hospice rotation, experience in developing training, developed education and integrating it into academic care curriculum. Said patients must understand the risk of staying home. Spoke more about a pilot program in St. Petersburg: pre-hospital care, taught paramedics that they read plan of care – provide palliative care, paramedics extend scope of practice, Living Will is not an EMS instrument.

The meeting was adjourned at 7:30 p.m.

**Minutes of The Panel for the Study of End-of-Life Care**  
**Tuesday, November 10, 1998**  
**Zephyrhills City Hall Zephyrhills, FL**

**Panel Members in Attendance:**

Representative Dr. Bob Brooks, Florida House of Representatives  
Dr. Marie E. Cowart, Pepper Institute on Aging and Public Policy  
Cathy Emmett, Florida Nurses Association  
Stan Godleski, Consumer Advocate  
Mary Alice Ferrell for Kenneth S. Rubin, The Florida Bar  
Marshall Kelley, Agency for Health Care Administration  
Mary Labyak, Hospice of Florida Suncoast  
E. Bentley Lipscomb, Department of Elder Affairs  
June Noel, Department of Elder Affairs  
LuMarie Polivka-West, Florida Health Care Association  
Dr. Alvin E. Smith, Oncologist, Florida Medical Association  
Dr. Howard Tuch, Genesis ElderCare  
Dr. Susan V. White, Florida Hospital Association

**Advisory Board Members:**

Rev. Celillon Alteme, Tampa General Healthcare  
Kate Callahan, Huntington Research Group  
Dr. David M. McGrew, American Academy of Hospice and Pain Medicine  
Henry Pearson, Pearson's Rest Home  
Freida Travis, Department of Health Bureau of Emergency Medical Services

Dr. Melissa A. Hardy, Pepper Institute on Aging and Public Policy

The meeting was called to order at 10:15 a.m. by Chairman Dr. Bob Brooks. Panel members, Alternates, and Advisory Board Members introduced themselves to the audience. Representative Carl Littlefield issued welcoming remarks and stated that Governor-elect Jeb Bush has made aging issues a priority. Representative Littlefield then joined the panel to listen to testimony.

Public Testimony: questions/comments were taken from the audience.

- ↳ Nancy Berg – Ms. Berg talked about the importance of public guardianship, especially for the elderly who are desperate for attention and funding for programs. From the panel, Dr. Smith responds and asks what the Florida Medical Association can do to help.
- From the panel, Mr. Lipscomb responds and states that an organization (e.g. church) cannot be a guardian, but some one individual from the church (non-profit corporate entity) can.
- Issues involved in guardianship and surrogate status
1. “substituted judgement” vs. “best interest”
  2. guardian (surrogate) – without clear written guidelines, cannot ask for level of care different from community standard
  3. “best interest” – community standard
- Ms. Berg comments on how there is a need to upgrade qualifications for guardians.



From the panel, Mr. Lipscomb responds and states that there is a trend towards support of public guardians in 3 districts and that numbers have progressively increased over time. Through education and certification, those who are in the guardian program for the wrong reason are weeded out.

From the panel, Dr. Tuch responds and mentions that the huge barrier to effective EOL care in nursing homes is the absence of decision makers for indigent patients.

From the panel, Mr. Kelley responds and states that we need to try and look for a solution that uses community groups.

✧ Bill Ebring, CARES (Community Aging and Retirement Services) – Mr. Ebring states that all home care clients funded through DOEA funds are asked about health care surrogacy by case manager. He feels we should work through that process.

✧ Home health aides should call EMS. They must present applicable DNR forms to EMS personnel.

✧ Person at home with home health aide and a medical event occurs:

- a. Call 911?
- b. Call physician?
- c. Call no one?
- d. Call alternate practitioner?

May already be dead or dying – HHA needs a “witness” to death but if no DNR, the EMT can treat and may transport to a hospital.

Issue of patient self-determination – HHA liability, legal expectations, potential for abuse, and no care when there should be.

✧ Dawn Woodward – AD, DNR, transfers among facilities, yellow DNR are not recognized in any facility. Nursing homes want to use their own forms rather than ones already completed. Must reinvent directives and the family must readdress issues if the patient is not competent. Uniform documentation needed.

✧ From the board, Ms. Travis comments that EMTs and nursing homes can work out these transmission issues.

✧ Nursing homes – own corporate legal interpretation of the law: to be 100% comfortable within legal framework, they need their own forms. Don’t believe DNR form is legal.

Can facilities just “opt out” of recognizing DNR forms

Hospitals recognize yellow DNR forms; nursing homes don’t.

✧ Need better information on what hospitals are doing. Medicare means that they must be offered advance directives at each hospitalization.

The Panel meets at 12 p.m. to wrap-up.

The Panel discusses legislative changes to be passed. Dates for January are considered: 1<sup>st</sup> week (1/5) and early the 3<sup>rd</sup> week (1/20) for first meeting of 1999.

Panel adjourned at 1 p.m.

**Minutes of The Panel for the Study of End-of-Life Care**  
**Friday, December 4, 1999**  
**Mary Singleton Senior Center Jacksonville, FL**

**Panel Members in Attendance:**

Samira Beckwith, Hope Hospice and Palliative Care  
Representative Bob Brooks, Florida House of Representatives  
Stephen Chaney for Dr. Winchester, Florida Board of Medicine  
Marie Cowart, Pepper Institute on Aging  
Cathy Emmett, Florida Nurses Association  
Mary Alice Ferrell for Ken Rubin, The Florida Bar  
Joan Fulbright, Association of Community Hospitals and Health Systems of Florida Inc.  
Marshall Kelley, Agency for Health Care Administration  
Mary Labyak, Hospice of Florida Suncoast  
E. Bentley Lipscomb, Department of Elder Affairs  
Molly McKinstry for Marshall Seiden, Florida Association of Homes for the Aging  
June Noel for E. Bentley Lipscomb, Department of Elder Affairs  
Dr. Robert Panzer, Florida Health Care Association  
Karen Peterson  
LuMarie Polivka-West, Florida Health Care Association  
Jackie Roberts for Jim Towey, Commission on Aging with Dignity  
Ken Rubin, The Florida Bar  
Marshall Seiden, Florida Association of Homes for the Aging  
Kelly Skidmore, Legislative Aide for Sen. Ron Klein, Florida Senate  
Dr. Alvin Smith, Oncologist, Florida Medical Association  
Dr. Howard Tuch, Genesis ElderCare  
Dr. Susan White, Florida Hospital Association

**Advisory Board Members:**

Rev. Celillon Alteme, Tampa General Healthcare  
Kate Callahan, Huntington Research Group  
Dr. Domingo Gomez  
Jane Hendricks, Attorney at Law  
Rev. Marilyn Mayse, University Medical Center  
Dr. Mike McCarron, Florida Catholic Conference  
David McGrew, American Academy of Hospice and Pain Medicine  
Ray Moseley for Ken Goodman, Forum for Bioethics and Philosophy  
Henry Pearson, Pearson's Rest Home  
Freida Travis, Department of Health Bureau of Emergency Medical Services

Melissa A. Hardy, Pepper Institute on Aging

Public Testimony.

Clark Fuller: Do not resuscitate order form is a problem. It is confusing to people; they don't understand in what contexts it applies or what other forms are necessary if the person is moved to a different facility. Difficult to have to fill out this kind of directive multiple times.

Shannon Kelley. Runs a 150 bed facility in Blountstown which includes an advanced Alzheimer's unit. Trying to respect patients' advance directives is difficult. One patient had a 20-30 page document detailing the kind of treatments she did and did not want under specific conditions. Even so, the family insisted on a feeding tube, though her living will specified that she did not want a feeding tube. The nursing home staff are often caught between patient wishes and family/physician treatment specifications. Because the patient was not diagnosed as terminal, it was determined that the living will did not apply.

Upon admission to nursing home, staff are required to go over documentation. This is often overwhelming to the patient and the patient's family because admission is such a stressful and emotional event. Why can't nursing homes use documentation that hospital transfers already have completed?

There is a lack of clarity on what a terminal condition is. Statute 765 does not use a clinical definition, yet physicians often invoke clinical guidelines when asked to make a determination.

I am often placed in the role of advocate for the patient. It is very difficult to get patient wishes honored. Nursing homes have an increasingly incapacitated population. I would like to see legal protection for the nursing home staff who advocate for patient wishes.

Marshall Seiden> Has your home developed an ethical position or protocol to deal with problem cases? Do you use any mechanism other than state guidelines?

Shannon Kelley> Concern is that nursing homes are always having to "reinvent the wheel." They are in constant contact with state, family and physicians to discuss difficult cases, but each case seems to present challenge to re-document procedures and reaffirm decisions.

Marshall Kelley> Are there any practical procedures to allow transfer of documents from hospitals?

Shannon Kelley> It would seem that whatever paperwork was completed in hospitals, for example, could just be forwarded with the patient rather than the nursing home having to rectify.

Dr. Smith> How can physicians help you?

Shannon Kelley> Would prefer physicians have frank discussions with patients about end-of-life issues; be sure patients understand when they are terminal. Nursing homes are required to have their own DNR orders; it is scary to talk about these issues upon admission to a nursing home. Patients are already trying to deal with the fact that they are being admitted to an institution in which they will, in all likelihood, die. To have to confront the specifics of their deaths is very difficult, but it is particularly difficult at that time. There is also confusion about the state DNR forms; the 1993 DNR order does not address terminal illness, so there is confusion as to whether terminal illness is required for the wishes to be applied.

Freida Travis> Both the 1993 and the 1995 forms require terminal illness. The only difference in the forms is that, in 1993, reference was made to the terms of Statute 765 (which requires terminal illness), but the form itself did not explicitly include the phrase "terminal illness." Because of the confusion, the 1995 form made this requirement explicit rather than through referral to another document. This issue has been raised many times and shows how much confusion can result from such a difference in wording.

LuMarie Polivka-West> Given that you are in a rural area, how could you establish an ethics committee?

Shannon Kelley> Don't really know what the logistics of establishing an ethics committee would be. Does an ethics committee protect the nursing home from legal liability?

Marshall Seiden> Need to correct something--an institutional provider is protected if they establish procedures and disseminate the information.

Dr. Poff> Introduced information about the Northeast Bioethics group and their recently formulated statement regarding physician assisted suicide. Noted that one major problem with DNR orders is that people are afraid that they will receive no treatment if they fill out that kind of form--that they will not benefit from other sorts of treatment that may make their dying easier. Well documented that patients with living wills do not receive the same quality of care in hospitals, so patients are concerned about the broader effects of these documents.

Also noted that there are various palliative groups in NE Florida, but they do not communicate. Much could be learned by sharing information, strategies and procedures as well as through general discussions of the ethical issues that are involved in many current situations.

Dr. Smith> In Switzerland, they train teams to assist in suicide; MDs train the team because the MDs cannot be on the scene. Why do we draw such a distinction between curative and palliative care? There are resources available for hospice care for those who choose not to be aggressive in their treatment, but what about resources to be used for curative care? Many patients who pursue more aggressive treatment plans could also benefit greatly from the kind of care and services that hospice provides. Why is that kind of care not more generally available to patients? Should we have palliative care fellowships or residency programs in the state?

Dr. Poff> We are terribly behind in training.

Dr. Tuch> It is important to help patients and families negotiate the last years of life.

Speaker> How does the system get initiated? Why call EMS and then tell them not to do something?

Freida Travis> There are lots of reasons someone might call an ambulance and still want a DNR order enforced. Home health aides may feel bound to call for help and let the EMTs decide about the DNR order; some people may not want the person to die in the home; others may not have experienced death and be uncertain as to the health status of

the patient. Whatever the circumstance, if EMTs are called, the intent of the document is to place a boundary on the kind of intervention the EMTs should make. If EMTs are called to a scene, they are not to automatically resuscitate, regardless of directives. They ask to see the form and, if the form is produced, it should be honored. But there is a very limited time frame in which all this must occur. They can't stand around and wait for people to search the house for a document that may or may not exist.

Cathy Emmett> DNR means do not resuscitate, not do not treat; in the presence of a DNR order you can (and should) still provide active, even aggressive comfort care. People-especially health care providers-need to understand that.

Break for lunch.

Afternoon Session.

Representative Brooks opened the session by noting that he would call on a presenter for each working group to make proposals and explain the rationale behind each proposal. Each working group was allotted 50 minutes. The Chair would entertain motions and allow voice votes unless a recorded vote was requested. The Chair noted that the Panel would have two more meetings to formulate recommendations, and that concisely worded motions would make the decision process easier.

Dr. Howard Tuch presented proposals from the Pain Management working group.

PMI. The Panel's attention was drawn to the first written recommendation that had been circulated to all members, i.e., "to create a positive citizen right to adequate pain management and care in the state of Florida."

Dr. Smith moved this recommendation with a second from Dr. Panzer.

Points of discussion:

1. Should we declare citizens' "right" to pain management or raise their expectations regarding the kind of care they should expect from their physicians?
2. What are the financial and legal consequences of creating a right?  
[Marshall Kelley noted that there were various patients' "Bill of Rights" documents to which this could be added, but noted that without enforcement authority, these rights would have questionable impact.]
3. Does creating a "right" mean that the state or health care insurance companies are required to assume the cost?
4. Use of "entitlement" language will create problems.

Dr. Smith made a substitute motion to refer the issue back to the working group (Dr. Panzer agreed). The substitute motion was adopted by voice vote.

PMII. The second recommendation was that the Panel propose the adoption of language that supports providers administering adequate pain management with the primary goal of alleviating the patient's pain, even if a collateral effect is to hasten the patient's death.

Dr. Tuch noted that a recent U.S. Supreme Court decision (case of Timothy Quill) referenced the appropriate nature of this type of care in written concurring decisions against physician assisted suicide (see O'Conner and xxx).

Discussion points:

1. Are there limits on “double effect?”
2. Confusion regarding what the “language” would be.
3. Are we limiting this treatment to terminally ill patients?

This issue was also sent back to the working group. Dr. Ray Moseley was asked to assist in drafting the language.

PMIII. “Create statutory language to establish rule authority to adopt pain management guidelines using the Florida Pain Management Guidelines, the American Board of medicine, and other national expert groups’ guidelines as models.”

The aim of this recommendation is to communicate expectations to medical professionals. Rule authority empowers patients as well as medical professionals.

Motion made by Dr. Tuch and second by Dr. Panzer.

Points of Discussion:

1. Dr. Smith noted that this was a very important thing to do, to clarify the guidelines that should govern practice.
2. Can we add “double effect” to this issue?  
[Adding it would complicate this issue and probably delay it.]
3. This mechanism allows rules of practice to be changed without changing the statute.
4. Dr. Winchester, who chairs the Florida Board of Medicine, developed this motion.

Question called. Adopted by voice vote; no dissenters.

Ken Rubin presented proposals from the Advance Directives Working group. He acknowledged the considerable assistance provided by members of the legal group at the Department of Elder Affairs, particularly P. K. Jameson, Meta Caulder, and Bob Jackson.

ADI. Working group recommends that “terminally ill” be struck from Statute 765.

Motion made by Rubin; second by Emmett.

Rationale. Under Florida’s constitution, the right to refuse treatment cannot be limited to those who are terminally ill. The courts have already established the right of a competent person to refuse treatment; advance directives are completed by competent people (i.e., those who have never been competent will not have advance directives); in advance directives, people specify treatments they want or treatments they do not want; inclusion of the limitation—“terminally ill”—in Statute 765 as the necessary precondition to honoring advance directives violates the constitutional rights of patients’ who have advance directives. Rights that competent people have when they are conscious cannot be rescinded because they lose consciousness or later become incompetent.

The use of “terminally ill” as a “barrier” to the invocation of advance directives is therefore vulnerable to legal challenge. Patients’ who want to have certain conditions

(e.g., being terminally ill) serve as a necessary precondition for the application of advance directives should so specify in their personal documents.

Limiting the use of advance directives to those with terminal illness cannot be required; but it can be specified by the individual and therefore required in those particular cases.

[Supporting documents distributed by P.K. Jameson.]

Points of Discussion.

1. It needs to be done, but it will be an uphill battle.
2. "Terminal" is not specified in 401, but because 401 invokes Statute 765, taking 'terminal' out of 765 also affects 401.
3. A patient's right to refuse treatment cannot be qualified by condition of treatment.
4. Is it possible that removing 'terminal' from the statute would make people without capacity vulnerable to actions of a guardian?  
[actions by guardians are subject to judicial review.]
5. This change allows individuals to express their choice(s) of triggering condition(s).
6. What about treatments that may be required during surgery but are "disallowed" in living will?  
[ Physicians/surgeons need to talk with patients so they understand the circumstances under which the patient wants the living will to apply. Living wills are not acute response directives; most surgeons will not take patient into operating room unless certain directives are rescinded.]
7. This change does not leave a gaping hole; patients are allowed to determine medical parameters for their care.
8. Surrogate invoked only when patient does not have reasonable probability of recovering capacity.
9. It is important to protect the rights of those without capacity, but it is at least as important to preserve the rights of those who have capacity.

The motion was tabled for further discussion. Recognizing uncertainty on the part of a number of panel members, Rep. Brooks requested that the working group develop a diagram (perhaps a decision tree) that illustrates how patients in various circumstances could be affected by this change. At the next meeting we can then address various types of situations so everyone is clear about who will be affected and how they will be affected.

LuMarie Polivka-West presented the major themes of the Regulatory and Financial working group. They had no specific motions to bring the panel at this time.

Major barrier to palliative care is the lack of financing for that care. It needs to be integrated into the health care continuum, but this integration will require a funding source. Possible steps include:

1. Asking that code 66.7 (Medicare palliative care) be utilized, even though it is a secondary code. Routine utilization of that code will allow an assessment of what is currently being done. This assessment will allow initial estimates of cost.
2. Realign health care dollars from acute to palliative care.
  - a. Legislature can direct agency to include palliative care in case-mix reimbursement formulae.
  - b. 6-month period of hospice is both insufficient and underutilized.

- c. Medicare/Medicaid hospice waiver needs to be based on other decision-makers; we need to develop an alternative and test it through a demonstration project; there has been no systematic study of the 6-month marker; it may make sense to spread hospice dollars over a longer period.
  - d. Ensure that Medicaid and managed care reimbursement include adequate care dollars at the end of life.
3. The perception of regulatory barriers for providing EOL care has become the barrier. Health care providers are concerned about providing care that is already protected through legislation. Provider education is crucial to improving the quality of care.
  4. Advance Directives must be portable across the health care continuum. Multiple forms being requested at multiple sites places an undo burden on patients and their families. We need to develop forms and protocols that can be shared across sites. A demonstration project would allow us to test strategies. How can forms follow the patient?

#### Points of Discussion.

1. Legislation already provides protection from liability to health care providers.
2. Staff in nursing homes who try to follow patient wishes may incur the displeasure of family members.
3. We could pilot a program that recognizes exemplary programs (e.g., Gold Seal).
4. If we ask nursing homes to form ethics committees, we need to provide some guidance and education regarding the development and use of ethics committees.

#### Other thoughts.

Hospice services are available to those who have accepted the imminence of their deaths. Is there some way to expand the scope of hospice care so that patients who choose more aggressive therapies also have access to the kinds of services offered through hospice? [A first step is to define hospice services and link those services to specific financing.]

We need a systemic approach to long term care that includes hospice.

Meeting adjourned.



**Minutes of The Panel for the Study of End-of-Life Care**  
**Wednesday, January 6, 1999**  
**Betty Easley Conference Center Tallahassee, FL**

**Panel Members in Attendance:**

Samira Beckwith, Hope Hospice and Palliative Care  
Representative Bob Brooks, Florida House of Representatives  
Marie Cowart, Pepper Institute on Aging  
Cathy Emmett, Florida Nurses Association  
Mary Alice Ferrell, alternate for Ken Rubin, The Florida Bar  
Joan Fulbright, Association of Community Hospitals and Health Systems of Florida Inc.  
Stan Godleski, Consumer Advocate  
Jack Gordon, Hospice Foundation of America  
Marshall Kelley, Agency for Health Care Administration  
Mary Labyak, Hospice of Florida Suncoast  
Molly McKinstry for Marshall Seiden, Florida Association of Homes for the Aging  
June Noel for E. Bentley Lipscomb, Department of Elder Affairs  
LuMarie Polivka-West, Florida Health Care Association  
Jackie Roberts for Jim Towey, Commission on Aging with Dignity  
Ken Rubin, The Florida Bar  
Marshall Seiden, Florida Association of Homes for the Aging  
Kelly Skidmore, Legislative Aide for Sen. Ron Klein, Florida Senate  
Dr. Alvin Smith, Oncologist, Florida Medical Association  
Jim Towey, Commission on Aging with Dignity  
Dr. Howard Tuch, Genesis ElderCare  
Dr. Susan White, Florida Hospital Association  
Dr. Gary Winchester, Florida Board of Medicine

**Advisory Board Members:**

Sonya Albury, Health Counsel of South Florida  
Kate Callahan, Huntington Research Group  
Dr. Domingo Gomez  
Ken Goodman, Forum for Bioethics and Philosophy  
Dr. Christine Guignard, Agency for Health Care Administration  
Jane Hendricks, Attorney at Law  
Wayne Maberry for Rev. Celillon Alteme, Tampa General Healthcare  
Dr. Mike McCarron, Florida Catholic Conference  
Dr. David McGrew, American Academy of Hospice and Pain Medicine  
Ray Moseley, Forum for Bioethics and Philosophy  
Freida Travis, Department of Health Bureau of Emergency Medical Services

Melissa Hardy, Pepper Institute on Aging  
Anna Cam Fentriss, Governmental Relations  
Bob Jackson, Department of Elder Affairs  
P.K. Jameson, Department of Elder Affairs  
Melanie Meyer, House Committee on Aging and Long Term Care  
Robert Pickels, for Congressional Representative Alan Boyd

Meeting called to order at 10:15am by Dr. Brooks, chairman.

## Introductions and Agenda

Focus on concepts and brief explanations on the workgroup topics.

Dr. Brooks will file in the House of Representatives by next week: an initial Bill, based on the work that the panel has done thus far.

Introduction of the new Secretary of the Dept. of Elder Affairs, Dr. Gema Hernandez.

Given that E. Bentley Lipscomb was serving as vice-Chair for the Panel, we need to elect a replacement. The vice-Chair position will be filled at the January 20<sup>th</sup> meeting.

## Pain Management/Palliative Care

Group leader: Dr. Tuch

1. Motion by Dr. Smith on the “precept” of Pain Management and Palliative Care  
2<sup>nd</sup> by Kelley Skidmore.

Discussion.

Amendment by Sonya Albury, changing “citizens” to “all persons” and striking “This workgroup of,” “of Florida,” “greater,” and “Through the recommendations listed below”

**(# 1) Should appear as follows: The Panel on End-of-Life Care believes that all persons should have access to effective pain management and palliative care services. Dying has become a difficult grace within our modern and technologically driven health care system. The Florida legislature can promote meaningful change in the delivery of medical care at the end of life.**

**Motion passed unanimously.**

2. Motion by Dr. Tuch on the “definition” of Palliative Care  
2<sup>nd</sup> by Dr. Smith.

**(# 2) Should appear as follows: Palliative Care is defined according to the World Health Organization: "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 possible quality of life for patients and their families."**

**Motion passed unanimously.**

3. Motion by Dr. Tuch on Recommendation #1  
2<sup>nd</sup> by Dr. Smith.

Discussion.

Jim Towey – over the use of “health-care facilities” terminology, is it inclusive enough to cover all end-of-life settings, including Assisted Living Facilities (ALFs)?

Dr. Tuch – highlighted the importance of including ALFs specifically because studies suggested that 20% of discharges are deaths, suggestion was made to add providers in addition to health care facilities and other organizations, because all end-of-life care does not occur in facilities

Samira Beckwith – this doesn't seem to be our primary concern, we've defined palliative care the same way "hospice care" is defined; use hospice as a means of care and not a provider

Mary Labyak – change "develop systems" to "improved care"

Dr. Gomez – change of dying and terminal to "end-of-life"

Dr. Smith – suggested taking out dying and terminal completely since pain should be alleviated for all patients

Dr. Tuch – suggested that we did need to focus only on end-of-life even though the issue is broader

Marshall Seiden – suggested replacing "seriously ill," "terminal," etc. all with "people at the end-of-life"

**Motion withdrawn. Decision to split motion into two (2) parts.**

4. Motion by Dr. Tuch on Recommendation #1 (part I)  
2<sup>nd</sup> by Dr. Smith.

Discussion.

Amendment by Dr. Winchester, changing "dying patients" to "people at the end-of-life"  
Amendment passed.

**(# 3) Should appear as follows: Health care facilities, other organizations, and providers caring for people at the end of life shall develop strategies to provide access to palliative care. Standards for pain management, management of other distressing clinical symptoms at the end-of-life, advance care planning and systems to attend to emotional and spiritual needs should be in place or available in all settings which care for seriously ill patients.**

**Motion passed unanimously.**

5. Motion by Dr. Tuch on Recommendation #1 (part II)  
2<sup>nd</sup> by Dr. Smith.

Discussion.

Amendment by Dr. McGrew, adding "Dept. of Elder Affairs" and changing "systems" to "strategies" and removing "in Florida health care facilities"  
Amendment passed.

**(# 4) Should appear as follows: The Agency for Health Care Administration and the Department of Elder Affairs shall be directed to develop or adopt reasonable standards to monitor the implementation and effectiveness of pain and palliative care strategies.**

**Motion passed unanimously.**

6. Motion by Marshall Kelley on adding the Rationale to Recommendation #1 “Such standards may include... (a. through f.)” and change “systems” to “strategies”  
2<sup>nd</sup> by Dr. Tuch.

Discussion.

Amendment by Dr. Winchester changing “dying patients” to “terminally ill people”

Amendment by Marshall Seiden changing “health care providers” to “providers”

Amendments passed.

**(# 5) Should read as follows (a. through f.):**

**Such standards may include:**

- a. Providing information regarding the options for care and support that exists within the local community.**
- b. Opportunity to participate in advance care planning and discussions of choices and decisions with appropriate providers**
- c. Develop excellence in pain management and the management of other distressing symptoms at the end of life.**
- d. Review / redesign of organizational policies and procedures that may pose barriers to or promote effective palliative care**
- e. Strategies to monitor and improve the effectiveness of pain management and organizational standards or end-of-life care**
- f. Interdisciplinary approaches to meet the social, emotional, spiritual and bereavement concerns of people at the end-of-life and their families**

**Motion passed unanimously.**

7. Motion by Dr. Tuch on Recommendation #2  
2<sup>nd</sup> by Dr. Winchester.

Discussion.

Amendment by Dr. Smith, changing “dying patient” to “people at the end-of-life”

Amendment passed.

Discussion.

Dr. Tuch – modify to “judicious,” but the point isn’t the word rather it’s the meaning  
Stan Godleski – the distinction of “aggressive” is important to noticing physicians of these changes in palliative care

Amendment by Marshall Seiden, removing “aggressive”

Amendment passed.

**(# 6) Should appear as follows: Pain management to achieve acceptable comfort for people at the end-of-life, when provided in full compliance with the Chapter XXX “Intractable Pain Statute” shall be construed as meeting the standard of medical care. Nothing in this recommendation shall be taken to promote or condone physician-assisted suicide or euthanasia.**

**Motion passed, 15-5. [reason for ‘no’ votes: wanted “aggressive” to be retained.]**

Break for Lunch at 12:00pm, Reconvened at 12:15pm

8. Motion by Dr. Tuch on Recommendation #3  
2<sup>nd</sup> by Dr. Smith.

**Motion withdrawn.**

9. Motion by Dr. Winchester on Recommendation #3, changing “Agency for Health Care Administration” to “appropriate quality assurance boards in conjunction with the Dept. of Health”  
2<sup>nd</sup> by Dr. Smith.

Discussion.

Dr. Winchester – by stating “quality assurance boards” we’re taking a pro-active stance, this will include not only hospitals but nursing groups, etc.

**(# 7) Should appear as follows: Health care boards shall adopt rules concerning guidelines for pain management.**

**Motion passed unanimously.**

Discussion on the next panel meeting.

- No more public testimony is really needed and time at the beginning of the meeting for workgroups
- 8am to 10:30am for workgroups and have the panel meeting last until about 4:30pm
- The next meeting will be in Tampa on Wednesday, February 24<sup>th</sup> (Airport Marriott?)
- Mary Labyak offered to help with meeting details

Advance Directives

Group leader: Kate Callahan (along with Ken Rubin)

Discussion about removing “Terminally ill” from Statute 765:

Ken Rubin – the workgroup suggests removing the “terminal” requirement in Statute 765; much of the public testimony that the Panel has heard has pointed out that it is hard to get physicians to agree on a terminal diagnosis; there is no need to have physicians document “terminal status,” it is an obstacle to people having their wishes met; removing “terminal” does not remove the responsibility of surrogates to make health care decisions

Meta Caulder – presentation:

If a patient has never had capacity, then they cannot under 765 create advance directives and default modes are used.

If a patient has capacity and remains in capacity, then the patient has the ability to create directives and make treatment decisions.

765 comes into play here... If a patient has capacity but then loses capacity.

1. Motion by Ken Rubin on the removal of “terminal” from Chapter 765  
2<sup>nd</sup> by Cathy Emmett.

Discussion.

Jim Towey – are there other states that have this type of statute? (765) why then does a state define “terminal” and use that as a basis for advance directives? simply removing

the word “terminal” will not solve all the problems with advance directives and having people’s end-of-life wishes met

Ken Rubin – use of “terminal illness” has caused problems for people to intervene

Jim Towey – the problem is compliance with people’s issues of intervening and not the stating of the statute; gerontology isn’t something that our physicians have an understanding of here in Florida, the care for our elderly; we as a panel haven’t gotten enough public testimony; we should hold off on making a statutory change and focus on the intermediate options and have those changes effect the statute as it stands

Frieda Travis – the original DNR forms don’t cover the cases of those who once had the capacity and don’t anymore

Cathy Emmett – access to basic health-care seems to be the issue; there are cases out there and this panel has heard from quite a few of these cases in public testimony of people who have run into a barrier with this issue of “terminal illness”

Mary Alice Ferrell – the biggest problem in guardianship is providing evidence of the patients wishes, this is the same with proxies (similar problem), we’re still going to act under the confines of the physician, we’re only removing a word that makes it a problem for the whole process of advance directives, removing the word terminal is not removing all safeguards

Cathy Emmett – the Browning case is actually the standard, what we’re trying to do is to raise the statute standard to meet the Browning case

Dr. Hardy – There is a problem with the meaning of “terminal” in the statute; as it stands, it depends on the definition that the physician applies whether or not a person’s wishes are met; we should only leave “terminal” in if we are satisfied with a clinical definition of terminal. However, we cannot just take out the word terminal in isolation from other issues in end-of-life decision making. We also need to look at 1) what information is available to those making living wills 2) how frequently a person revisits their end-of-life choices 3) if the decision is communicated or not. The issue is whether those who have these options really do understand these options and if there are those that don’t and need it, then there needs to be a modification. There also needs to be an understanding of information that can be known and researched and disseminated to physicians, health-care groups, and legislative bodies

Ken Goodman – the definition of “terminal” isn’t easy to understand as is, the move towards changing the statute should be to help educate and inform the public on what standards there are that exist

Dr. Moseley – removing “terminal” because of the ambiguity will only move the battle to the issue of competency and capacity and may not result in more ADs being honored

Dr. McCarron – we need to be very sure this is a wise choice before doing something that will be viewed as very significant

Mary Labyak – some change is necessary, whatever it is though it must be made, because it is a wall that exists and inhibits care from physicians, health-care groups, etc... the perception that is out there is that you need to be on the brink of death for any help to be given

Marshall Seiden – the Browning case is the norm even to physicians, there are however these problems created with the use of the language “terminal”

LuMarie Polivka-West – we need to be responsive to the public’s wishes to remove “terminal” as a stumbling block, and also recognize the need to also focus on the educational component

**(# 8) Should appear as follows: Recommend that the legislature remove from F.S. 765 the requirement that a person be “terminally ill” before life-prolonging procedures can be withheld or withdrawn.**

**Motion passed, 19-1.**

2. Motion by Ken Rubin on a standardized DNR order  
2<sup>nd</sup> by Cathy Emmett.

Discussion.

Kate Callahan – the physician and patient come to an agreement that there is a need for a DNR order, the issue is to create one standardized order that will follow the patient until death for change in that order

Freida Travis – need something besides a uniform paper form, need a different medium because that was the intention of the “yellow” form we now have and it hasn’t worked

Dr. Smith – supported the idea of a transportable DNR order, would help all

**(# 9) Should appear as follows: Recommend the legislature create a standardized and portable DNRO form that can be used in all patient settings. Create policy and procedures to implement the effective use of this form.**

**Motion passed unanimously.**

Financial/Regulatory Issues

Group leader: LuMarie Polivka-West

1. Motion by LuMarie Polivka-West on Preamble suggestions  
2<sup>nd</sup> by Dr. Cowart.

Discussion.

(individual line-items passed separately)

**(# 10) Recommendation #1 passed unanimously.**

**Should appear as follows: There is a need for a societal change in understanding and supporting good end-of-life care. Treatment patterns of physicians, decisions by family members and the terminally ill individual, and understanding by the larger community will be effected by an understanding of good end-of-life care and the opportunity to experience a quality life until the very end.**

**#2 tabled.**

**(# 11) Recommendation #3 passed unanimously.**

**Should appear as follows: Support the right to refuse treatment and the patient's right to make decisions about their care and their surrogate's right to carry out the patient's wishes when they are no longer capable of decision-making.**

**#4 tabled.**

**(# 13) Recommendation #5 passed unanimously. (with the change of “responsibility” to “obligation” and “aggressive” to “curative”)**

**Should appear as follows: The right to die without aggressive curative treatment does not equate to an obligation to die at any age or any disability. This 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.**

**(# 14) Recommendation #6 passed unanimously.**

**Should appear as follows: Realign existing financial resources to appropriately reimburse for palliative care.**

**(# 15) Recommendation #7 passed unanimously.**

**Should appear as follows: All persons, regardless of insurance status, should be provided with access to good end-of-life care.**

Discussion on “strategies”:

Dr. Winchester – suggested that Deans will fight this if we tell them what their curriculum needs to be; this may be detrimental to the overall plan of the Panel and moving the rest of its suggestions forward

Marshall Seiden – we shouldn't concentrate on a new medical school, but on having the legislature urge current medical schools to revise their curriculum

The next meeting will be on January 20<sup>th</sup> at 9am – 4:30pm at the Dept. of Elder Affairs with the same agenda.

Panel adjourned at 4:15pm



**Minutes of the Panel for the Study of End-of-Life Care**  
**Wednesday, January 20, 1999**  
**Betty Easley Conference Center Tallahassee, FL**

**Panel Members in Attendance:**

Susan Acker, alternate for Marshall Kelley, Agency for Health Care Administration  
Dr. Bob Brooks, Secretary, Florida Department of Health  
Marie Cowart, Pepper Institute on Aging and Public Policy  
Cathy Emmett, Florida Nurses Association  
Mary Alice Ferrell, alternate for Ken Rubin, The Florida Bar  
Joan Fulbright, Association of Community Hospitals and Health Systems of Florida Inc.  
Stan Godleski, Consumer Advocate  
Carl Littlefield, alternate for Gema G. Hernandez, Department of Elder Affairs  
Marshall Kelley, Agency for Health Care Administration  
Mary Labyak, Hospice of Florida Suncoast  
Molly McKinstry for Marshall Seiden, Florida Association of Homes for the Aging  
LuMarie Polivka-West, Florida Health Care Association  
Jackie Roberts for Jim Towey, Commission on Aging with Dignity  
Kelly Skidmore, Legislative Aide for Sen. Ron Klein, Florida Senate  
Dr. Alvin Smith, Oncologist, Florida Medical Association  
Dr. Howard Tuch, Genesis ElderCare  
Tanya Williams, alternate for Dr. Gary Winchester, Florida Board of Medicine

**Advisory Board Members in Attendance:**

Sonya Albury, Health Council of South Florida  
Rev. Celillon Alteme, Tampa General Healthcare  
Kate Callahan, Huntington Research Group  
Ken Goodman, Forum for Bioethics and Philosophy  
Jane Hendricks, Attorney at Law  
Dr. Mike McCarron, Florida Catholic Conference  
Dr. David McGrew, American Academy of Hospice and Pain Medicine  
Ray Moseley, Forum for Bioethics and Philosophy

Dr. Melissa A. Hardy, Pepper Institute on Aging and Public Policy

Meeting called to order at 9:30am by Carl Littlefield, acting-Chair.

Announcements.

Election of a new vice-Chair will occur later today.

Motion by Dr. Smith to accept the Minutes of the December 4<sup>th</sup> and January 6<sup>th</sup> Meetings.  
2<sup>nd</sup> by Kelly Skidmore.

Motion passed unanimously.

Carl Littlefield handed over the Chair to Dr. Brooks.

Financial/Regulatory Issues Workgroup:

Leader: LuMarie Polivka-West (Handout, included as an attachment)

Motion by LuMarie Polivka-West on Recommendation #1.  
2<sup>nd</sup> by Dr. Smith.

Discussion.

Dr. Smith – this is a foolish idea. We need to turn our energies towards coming up with innovative ideas to get physicians on board. The FMA will not support this recommendation. Neither will other professional organizations. It will create resistance and you will spend all your time fighting. It's too simple. We need to find innovative ways to educate.

Dr. McGrew – agreed with Dr. Smith. We need to encourage education versus legislate requirements.

Dr. Brooks – introduced an alternative motion, suggesting that the legislature allow physicians etc. to take CME classes on end of life care in place of other mandated classes.

LuMarie Polivka-West – this has been an issue that has come up at every meeting but we never passed anything as a Panel concerning this and wanted the Panel's input.

Susan Acker – The problem with substitution is the public health implications of not receiving continuing education in the other subject areas (such as the AIDS, domestic violence series).

Dr. Smith – if we continue to mandate education, doctors aren't going to have time to learn all of this information; let's find an innovative program to disseminate this information.

Susan Acker – we don't stand against innovation, but we need to get this information out in some way and get this legislature talking about how this will take place (education)

Mary Labyak – we all agree on the goal, the question is how to get there. We need to get more knowledge to health care professionals about end-of-life care. We need to change core beliefs and values. EOL training could be substituted for AIDS education if the person already has received the training.

Kate Callahan – continuing education requirements are 30 hours every 2 years.

Incentives for participation may be discounted malpractice insurance, or discounts on professional association membership.

Dr. Brooks – Recommending that these organizations suggest and come up with ways to offer incentives isn't a bad idea; highlight EOL education to them as a great thing to consider.

LuMarie Polivka-West – If the AIDS requirement has been met in previous years, the EOL education could be substituted for HIV/domestic violence or risk management education. She recommended we endorse the development of innovative educational programs.

Dr. Brooks – suggested changing the wording from “legislate” to “recommend”

Mary Labyak – Recommended a substitute amendment with the wording changes and recommended adding in the clergy.

Dr. McGrew – reword the motion to state “up to 3-4 hours” and not include the substance of the class or what it can be substituted for.

Dr. Brooks handed over the Chair to Carl Littlefield.

Substitute amendment motion withdrawn.

(motion passed back to the Financial/Regulatory Issues Workgroup for re-wording – motion made by Dr. Smith, 2<sup>nd</sup> by Mary Labyak, motion passed unanimously)

Motion by LuMarie Polivka-West on Recommendation #'s 1 and 2 (combination).

2<sup>nd</sup> by Dr. Smith.

Revised wording of motion:

**The Florida Legislature recognizes the vital importance of good end-of-life education for all people practicing in health care, human services and related areas. These needs begin to be addressed by the legislature adopting the following recommendations:**

**(#1) that continuing education in end-of-life care may be substituted for any of the current mandatory continuing education requirements (when these requirements have been met in previous cycles) for, professions that include, but are not limited to physicians, nurses, social workers, pharmacists, administrators of health care facilities, clergy and lawyers.**

**(#2) that the legislature encourage the ongoing development of innovative end-of-life educational programs for all health care providers.**

**(#2a) that the Legislature recommend that professional organizations representing the aforementioned groups develop strategies to promote and provide incentives for participation in end-of-life training and that these professional organizations incorporate end-of-life education in their on-going organizational activities.**

**Motion passed unanimously .**

Motion by LuMarie Polivka-West on Recommendation #3  
2<sup>nd</sup> by Dr. Smith.

Discussion.

Ken Goodman – we may want to include some other organizations in this work group.

Dr. McGrew – offer pros and cons of particular education; issue of problems of changing the curriculum of the four (4) Florida medical schools.

Sonya Albury – suggested that health services administrators be included.

LuMarie Polivka-West – we could add “and one representative from...” so that the list of representatives that would comprise this work group is left open.

Ray Moseley – has the workgroup collected model curriculum from various schools?; the people you should have on this work group are the curriculum committee chairmen from these various schools, these are the people in charge of the curriculum; having them a part of this would save a step.

Kelly Skidmore – these curriculum chairmen would be a great addition to this work group but they shouldn't be the sole members.

Ray Moseley – this seems terribly inefficient.

Dr. Cowart – the approaches are different but the idea is to keep the group small so that materials could be gathered together.

Dr. McGrew – this is an interdisciplinary subject matter, so it makes sense to have a work group comprised of members from many different disciplines (such as medicine, social work, etc.)

**Motion passed unanimously as follows:**

**(#3) That the Legislature authorize the creation of a work group comprised of but not limited to a representative from the Board of Medicine, the Board of Osteopathic Medicine, the Board of Nursing, the Board of Pharmacy, the Board of Nursing Home Administrators, one School of Medicine, one School of Social Work, and Chairs of the four (4) Florida medical schools' curriculum committees, review available curricula on end-of-life care and make recommendations through the respective Boards for curriculum materials to be incorporated into the basic curriculum of each school of medicine, nursing, social work, pharmacy, and other health related disciplines.**

Motion by LuMarie Polivka-West on Recommendation #4.  
2<sup>nd</sup> by Dr. Smith.

Discussion.

Dr. Tuch – need to produce innovative approaches for the multicultural diversity of communities

Mary Labyak – education is a one-way communication; we need to engage the public

**Motion passed unanimously as follows:**

**(#4) Create incentives for health and elder care providers, and for publicly accessible media such as the press and public radio and television, to encourage public dialogue about Advance Directives and end-of-life care options. Incentives might take the form of citation in annual ratings for providers, and private funding for public radio and television productions that reflect the multicultural diversity in our communities.**

Motion by LuMarie Polivka-West on Recommendation #5.  
2<sup>nd</sup> by Stan Godleski.

Discussion.

Dr. Cowart – is there any value in including nursing homes and ALFs (assisted living facilities)?

Dr. Tuch – there is an overlap in recommendations from the different work groups; a good program can mean different things in different places. We want to encourage excellence. Our role is to encourage providers to develop systems not to tell them what they are because there will be a lot of variability. It's helpful to keep it vague rather than too specific.

Carl Littlefield – we're merely making recommendations to this legislature; we're kicking these issues around and it will be this legislature that will deal with the specifics.

LuMarie Polivka-West – the original recommendation, reflected in the Jan.6 minutes, was very unclear; we wanted to make this clearer

Susan Acker – would not be eligible for a Gold Seal without an end-of-life component.

Dr. McGrew – we need to recognize the presence of excellence in end-of-life care that includes such things as...

Dr. Tuch – however we want to be careful not to limit good end-of-life care to very specific things.

**Motion passed unanimously in concept:**

(recommendation passed back to the Financial/Regulatory Issues Workgroup for rewording – motion made by Dr. Smith, 2<sup>nd</sup> by Mary Labyak, motion passed unanimously)

Revised wording of motion:

**(#5) Institute a legislative proposal that encourages excellence in end-of-life care. Criteria of excellence should include but not be limited to: 1) a mechanism for effective conflict resolution regarding end-of-life decisions (e.g. an active ethics committee) 2) a facility-based palliative care program 3) and/or a formal affiliation with a hospice organization. Such conditions should define eligibility for awards recognizing excellence in health care facilities (e.g. a Gold Seal award for nursing homes).**

**Motion passed unanimously.**

Motion by LuMarie Polivka-West on Recommendation #6.  
2<sup>nd</sup> by Dr. Smith.

Discussion.

Dr. Tuch – conflict between “good end-of-life care” and other perceptions of what is required of providers; don’t think that the problem is in the statutes themselves, but is in the conceptual understanding of them. A peaceful death in a nursing home is a reasonable goal and should not be discouraged by regulations.

Dr. Smith – does this include transitional care units? (no – under chapter 395)

**Motion passed unanimously as follows:**

**(#6) Recommend that the Legislature insert into F.S. Chapter 400, part II, and Chapter 395.1055(3), the inclusion of “good end-of-life care” as evidenced by a system to improve pain and symptom management, provide advanced care planning, and psycho/social support, as a part of meeting the OBRA mandate of providing the “highest practicable level of care.”**

Motion by LuMarie Polivka-West on Recommendation #7.  
2<sup>nd</sup> by Dr. Smith.

Discussion.

Mary Alice Ferrell-the protection is already in the law.

Dr. Smith – was unaware that this provision existed, but it is a constant problem for physicians. This law should be explained to all providers.

LuMarie Polivka-West – the intent is to add protective language and elevate these concerns

Dr. McGrew – was also unaware that the provision was already in the law. But this issue is still a problem that gets in the way of physician’s decision making. With the law in place there may be no criminal ramifications, but a law suit, even if it does not have legitimacy, still has high costs for the physician.

Molly McKinstry – suggested putting a statement in the licensure legislation

Dr. Smith – physicians need to be reassured that they are protected

June Noel – can we add language from chapter 400?; this also should include nursing homes and ALFs

Susan Acker – added to statutes involved in regulation of providers and facilities

Cathy Emmett – need to put language in the Board of Medicine Statute

Ray Moseley – one way to reassure physicians is to put a statement in the ‘model’

Advance Directive form that the physician is obligated to follow the Advance Directive but is protected; will help make the family aware of this coverage

Kate Callahan – the family that is unaware of the Advance Directive is the problem; may help to include a space on the form for the person to include names of family members who may object to their decision.

Mary Alice Ferrell-suggested changing ‘provide protection’ to strengthen or enhance protection, since it is already provided for in the law.

**Motion passed unanimously in concept:**

(recommendation passed back to the Financial/Regulatory Issues Workgroup for re-wording – motion made by Kelly Skidmore, 2<sup>nd</sup> by Dr. Smith, motion passed unanimously)

Revised wording of motion:

**(#7) Recommend that the Legislature add to F.S. Chapter 765.109, language to enhance protection for provider actions taken in accordance with the individual’s oral or written Advance Directive statements that have been expressed by a competent informed and un-coerced adult and appropriately activated; and that such language be added to the respective statutory provisions governing health care providers and health care entities.**

**Motion passed unanimously.**

Motion by LuMarie Polivka-West on Recommendation #8.  
2<sup>nd</sup> by Dr. Smith

Discussion.

Stan Godleski – endorsed a standard uniform form for consumers. He likes the clarity of Oregon’s forms, this could be a good model for us. In addition to a universal form he wanted to emphasize the importance of educational efforts.

Dr. Smith – Oregon is very homogenous; it would be hard to translate that to a very complex state like Florida.

Dr. McGrew – I think this concern comes from the DNR order issue; the problem is the portability of the DNR order form from the hospital to the nursing home to ...etc.

Cathy Emmett – the Oregon example (from Stan Godleski) is basically a DNR order; portability is across all the facilities affected

LuMarie Polivka-West – the DNR form was our primary focus of concern but it is only one part of the Advance Directive. We heard public testimony about redoing the Advance Directive form. Our group wanted to keep it broad and not overlook an individual’s right to verbal agreement.

June Noel – believes that this one issue would take at least a year to look at; suggested that we propose in the legislation more research in this area, on DNROs in hospitals, in the home, verbal/oral directives etc. We haven’t studied the country to see what’s going on. We shouldn’t assume improved portability takes the form of one form.

Dr. McGrew – did not think that such research would take that long

Dr. Smith – can institute the DNRO without study, but we really do need more research on Advance Directives; we need to ensure that this distinction is made to the public and the physicians

Joan Fulbright – we’re confusing the consumer by requiring a different method for physicians’ orders and the patients’ wishes

**Motion passed in concept with 1 dissenting vote (Mary Alice Ferrell):**

(recommendation passed back to the Financial/Regulatory Issues Workgroup for rewording – motion made by LuMarie Polivka-West, 2<sup>nd</sup> by Dr. Smith, motion passed unanimously)

Revised wording of motion:

**(#8) Recommend that the Legislature provide for the portability of Advance Directives including a standard DNRO form that will be aligned with complementary public information and public education. Establish a work group under the auspices of the end-of-life advisory panel to develop a standard DNRO form that will be accepted and used among all providers in the continuum of care. The advisory group will be comprised of the involved providers and a representative of the Elder Law Section of the Florida Bar.**

**Motion passed with 1 dissenting vote (Mary Alice Ferrell) in opposition to the use of forms.**

Break for Lunch @ 12pm

Carl Littlefield handed over the Chair to Dr. Brooks.

Nominations open for “new” Deputy-Chair:

- Dr. Smith
- Dr. Cowart

Nominations closed.

The newly-elected Deputy-Chair: Dr. Cowart.

Motion by LuMarie Polivka-West on extending the Panel for at least another year until Aug. 2000.

2<sup>nd</sup> by Dr. Smith.

Dr. Brooks – the Panel itself can change the structure at any time

LuMarie Polivka-West – suggested an amendment to the Bill on the Statute, Section 3 (2)(j) to add in the Secretary of the Department of Health as an additional member.

Kelly Skidmore – yes, starting from scratch would be difficult

Rev. Alteme – if we continue this Panel then we need to consider getting a more culturally diverse group of individuals, particularly more Hispanic representation.

Dr. Brooks – spoke about the Panel selection process and ways to increase minority representation

Molly McKinstry – where can we find the funding to continue? Is there a way to offset the cost to the Pepper Institute on Aging, the main staffing body of this Panel?

Dr. McGrew – we should consider reimbursement for not only the Panel members but for their alternates and Advisory Board members

Dr. Brooks – we can recommend legislative funding for administrative costs and help to defray the expenses of the Advisory board members.

Jane Hendricks – will this delay the submission of the final report?

Dr. Brooks – we can make a recommendation to this legislature that would advise them that another interim report will be handed in on Aug. 1999 and that a final report will follow after that in Aug. 2000 (note: the final report would have originally been turned in on Aug. 1999)

Mary Alice Ferrell – is there an avenue open to obtain more funding for further or advanced research in some of the areas that we have focused on, or possibly new areas that we can look into?

Dr. Brooks – if we can get some funding to continue from this legislature, that would be a good start

**Motion passed unanimously as follows:**

**(#9) Amend Florida Statute 430.707, Section 3(6), to extend the Panel for the Study of End-of-Life Care until August 1, 2000; add to Section 3(2),”(j) The Secretary of the Department of Health, or his designee”, to serve as an additional member; add to Section 3, (3) line 6: “with funds appropriated for administrative and operational expenses;” and delete from Section 3(5)”final” before “report by August 1, 1999 ...”**

Motion by LuMarie Polivka-West on Recommendation #11 (also including the collapsed Recommendations #'s 9 and 10), concerning Medicaid reimbursement.  
2<sup>nd</sup> by Dr. Smith.

Discussion.

Marshall Kelley – we may need to add a staff member to the Panel from the House and Senate Appropriation Committees to adequately deal with the issue of Medicaid reimbursement. Most of the motion would take legal approval.

Mary Labyak – we may want to collapse Recommendations numbers 12, 14, and 15 into this motion as well, these would be the charge of the working group.

LuMarie Polivka-West – this motion is to create a workgroup to deal with Medicaid reimbursement and the collapsed recommendations are simply the guidelines that they will be given.

Rev. Alteme – add “pastoral care/counseling” to Recommendation #9 to fit under the guidelines

Dr. Tuch – urged caution in language of reimbursement; don’t want to take Hospice services apart and allow separate reimbursement; don’t want to suggest that only Hospice will work

Mary Labyak – give sanction to the community services associated with Hospices

Molly McKinstry – We should spell out places that need work; where we may be able to provide reimbursement for palliative care; we identified possible barriers in the Pain Management/Palliative Care Workgroup.

**Motion passed unanimously as follows:**

**(#10) Establish a working group made up of a representative from the Florida Legislature, staff representation from the House and Senate Appropriations committees, the Agency for Health Care Administration, the Department of Elder Affairs, the Department of Health, and representatives from the respective provider**



**associations to examine reimbursement methodologies for end-of-life care such as consultative hospice service and a Medicaid case-mix reimbursement of palliative care; to develop recommendations for incentives for appropriate end-of-life care of a high standard that will allow for more timely palliative and hospice care and enable all providers along the health-care continuum to participate in an excellent standard of end-of-life care.**

Advance Directives Workgroup  
(Handout, included as an attachment)

Motion by Dr. Brooks on Recommendation #3.  
2<sup>nd</sup> by Marie Cowart.

Discussion.

Ken Goodman – DNROs for whom -- outpatients? Change wording to pre-hospital.  
Marshall Kelley – to do some of these things would require time and money; where is that funding coming from?

Tanya Williams – Does the Department have the authority to find private funding for demonstration projects?

Marshall Kelley - The Legislature could set up a mechanism that would allow the Department of Health to set up demonstration projects.

**Motion passed unanimously as follows:**

**Providing for “demonstration projects” by local communities in conjunction with the Department of Health as to mechanisms for implementation of pre-hospital DNROs.**

Motion by Dr. Brooks on Recommendation #4.  
2<sup>nd</sup> by Marie Cowart

Discussion.

Susan Acker – question about the use of the word competency vs. capacity

Mary Alice Ferrell – the proper word is capacity (this is what is used in F.S. 765.204); is the second signature a necessary safeguard?

Dr. Brooks – How practical/feasible is the 2<sup>nd</sup> signature? Is one enough?

Dr. Smith – The 2 physician rule is not followed now; 1 is enough.

Cathy Emmett – its not necessary; if there is a question on the part of the primary physician, there is a consultation, a second physician would be called in.

Dr. Tuch – in the nursing home environment it is difficult to get a second physician’s signature; there are times when it is burdensome; He has mixed feelings as to whether it is a safeguard or not.

Marshall Kelley – Shared Dr. Tuch’s concerns. There is a real difficulty getting physicians to come into nursing homes. Using nurse practitioners or RNs or standing ethics committees would be appropriate. This might encourage nursing homes to develop ethics committees.

Mary Labyak – I would favor two people, but rather a second person from a health-care community

Dr. Smith – the nurse tends to be a caregiver and makes decisions similar to a caregiver, where the physician treats; so, it may be a better idea to have the second person not be another physician

LuMarie Polivka-West – one of the major problems is getting physicians to come into nursing homes; the recommendation to allow a nurse practitioner to be that second person is more feasible; or look into having someone from an ethics committee or clergy

Tanya Williams – Capacity is not limited to dementia. She recommended spending more time on this and inviting mental health representatives to speak to the Panel. The decision to allow only one person to make the determination is very serious. It is prudent to look at other mental health laws that deal with the issue of capacity.

Jane Hendricks – alternate suggestion; if you have an Advance Directive require one signature, if there is nothing, require two signatures in order for a proxy to make decisions; this could be an ARNP, MSW etc.

Dr. Brooks – do we need to designate who that second person is? I don't think that we should

Mary Alice Ferrell – we could word it so that there is a choice from a list of acceptable persons for the second signature.

From the Guardianship Statute which deals with competency issues for all types of populations, Mary Alice Ferrell provided a list of potentially acceptable persons: psychologists, gerontologists, nurse practitioners, licensed clinical social workers, ARNPs, physicians assistants.

#### **Motion passed unanimously as follows:**

**If a legally executed Advance Directive has been executed, we recommend the requirement of the assessment and evaluation of one physician as to the patient's capacity. In the absence of a legally executed Advance Directives, we recommend two (2) physicians or one physician and one of the following professional licensed health care providers: ARNP (advanced registered nurse practitioner), PA (physician's assistant), Psychologist, LCSW (licensed clinical social worker) determine the patient's capacity.**

Motion by Dr. Brooks to separate #5 and the bulleted part of this recommendation into two parts.

2<sup>nd</sup> by Dr. Smith.

Discussion.

Does the statute impose a legal obligation to recognize an Advance Directive?

Jane Hendricks – yes, there is a duty to follow Advance Directives.

Tanya Williams – it's a violation of practice acts not to fulfill legal obligations. It's a professional regulatory issue. There is already legal and disciplinary recourse; she reemphasized that appropriate Boards need to take action.

Molly McKinstry – the issue of communication of desires is important; the term "willful" is critical.

Stan Godleski – I am against any kind of penalty, because our main concern should be for education; why are we now suddenly concerned with imposing a penalty on these physicians?

Dr. Smith – the Boards and the FMA would react strongly to criminalization.

Mary Alice Ferrell – my understanding is that this penalty was going to be handled in a civil nature; I think consumers would want to have some penalty for physicians who do

not follow through with Advance Directives. Also, its not just physicians who should be subject to this. Its important to give people recourse if a properly executed Advance Directive is ignored. Willfully and knowingly is a higher standard, its not an everyday situation that a physician knew of an Advance Directive and did nothing about it. Ray Moseley – the vast majority of these cases are genuine cases of conflict problems dealing with communication issues; in these cases an ethics committee can step in and intervene; we should focus on the minority of cases where physicians ignore willfully the patient’s Advance Directive and not on penalizing those physicians who merely do not understand them (which is what the motion sounds as though it is suggesting) Cathy Emmett – who then would come forward to charge these physicians with disregarding Advance Directives? Dr. Brooks – I’m hearing that the legislation should clarify that willfully failing to comply could be cause for action.

Motion was tabled until next meeting.

Break at 3:15pm, reconvene at 3:30pm.

Palliative Care/Pain Management Workgroup  
Leader: Dr. Tuch (Handout, included as an attachment)

Discussion on amending previously passed motion.

Dr. Tuch – concern over the wording “judicious” as it relates to palliative care and pain management; doesn’t want meaning to be cautious or conservative. Need to frame language to raise the standard, not to accept the current standard, but also not to interfere with the Intractable Pain Statute. The core of the problem is in the statute “ a reasonable prudent physician under similar conditions and circumstances..” but in the statute there are no standards for “prudent”, only as a measure of behavior relative to other physicians. Tanya Williams- suggested that Boards be given rule making authority to develop practice standards for pain management at the end of life.

Dr. Tuch – Our purpose is to write language to influence the behavior of nurses, hospitals etc. who are afraid to give pain medications because it may shorten life and they may be held accountable.

Dr. Brooks – suggested that we encourage the consideration of adopting higher standards, and then recommend that health care boards adopt rules concerning guidelines for pain management.

June Noel – should include an educational piece; it is not just a matter of raising standards and rules, but there is a need to require people to know about these standards.

Motion by Dr. Tuch on Recommendation #3 (part I).  
2<sup>nd</sup> by Kelly Skidmore

**Motion passed unanimously as follows:**

**The Panel recognizes that too many Floridians are dying without adequate pain management. To provide appropriate pain relief to patients, particularly patients at the end-of-life, we recommend that health-care boards shall adopt rules concerning guidelines for pain management. We also recommend that these boards develop and promote educational programs to disseminate information regarding these rules and practices.**

Motion by Dr. Tuch on Recommendation #3 (part II, preface and professional education section only).  
2<sup>nd</sup> by LuMarie Polivka-West.

**Motion passed unanimously as follows:**

**The Florida legislature should adopt language to promote the following recommendations:**

**1. Professional education**

- g. encourage medical, nursing, social workers, pharmaceutical schools throughout the state to review and implement curricula designed to train in principles of pain management and palliative care.**
- h. encourage developed of materials and courses designed to educate practicing health-care professionals on appropriate standards of pain management and palliative care.**
- i. to promote specialist training programs (palliative care fellowship programs) for physicians in each of Florida's medical schools.**
- j. to promote specialist training programs for nurses, nurse practitioners, pharmacists, social workers to create a cadre of palliative care specialists.**
- k. to promote increased and earlier referral to hospice programs for appropriate patients.**
- l. establish a program on end-of-life care at the Pepper Institute on Aging to serve as a center of research and policy analysis on end-of-life care in the state.**

Motion by Dr. Tuch on Recommendation #3 (part II, public education section only).  
2<sup>nd</sup> by Stan Godleski.

**Motion passed unanimously as follows:**

**2. Public education**

- c. create a state-wide education campaign to improve understanding of palliative care, enhance access to hospice and palliative care services and to promote understanding of the need for advance care planning and Advance Directives.**
- d. create culturally sensitive education programs to improve end-of-life care in minority communities.**

Motion by Dr. Tuch on Recommendation #3 (part III).  
2<sup>nd</sup> by LuMarie Polivka-West.

Discussion.

June Noel – include those who don't qualify for Hospice or are not insured.

Amendment – adding to the end: "...and those without health-care insurance."

Amendment passed.

**Motion passed unanimously as follows:**

**The Florida Legislature should designate specific funding of studies to determine the clinical needs, costs and services available to Floridians dying at home, hospice,**

**hospital, assisted living centers, nursing homes, and those without health-care insurance.**

The next meeting will be on Wednesday, February 24<sup>th</sup> at 8:30am – 4:30pm at the Airport Marriott in Tampa, FL.  
Panel adjourned at 4:20pm.

**Minutes of The Panel for the Study of End-of-Life Care**  
**Wednesday, February 24, 1999**  
**Tampa Marriott Hotel, Tampa, FL**

**Panel Members in Attendance:**

Susan Acker, alternate for Pete Buigas Agency for Health Care Administration  
Samira Beckwith, Florida Hospice Association, Hope Hospice and Palliative Care  
Dr. Bob Brooks, Secretary, Florida Department of Health, alternate for Robert Panzer,  
Florida Osteopathic Medical Association  
Marie Cowart, Pepper Institute on Aging and Public Policy  
Cathy Emmett, Florida Nurses Association  
Mary Alice Ferrell, alternate for Ken Rubin, The Florida Bar  
Joan Fulbright, Association of Community Hospitals and Health Systems of Florida Inc.  
P.K. Jameson, alternate for Gema G. Hernandez, Department of Elder Affairs  
Mary Labyak, Hospice of Florida Suncoast  
LuMarie Polivka-West, Florida Health Care Association  
Kenneth Rubin, The Florida Bar  
Marshall Seiden, Florida Association of Homes for the Aging  
Dr. Alvin Smith, Oncologist, Florida Medical Association  
Jim Towey, Commission on Aging with Dignity  
Dr. Susan White, Association of Community Hospitals and Health Systems of Florida,  
Florida Hospital Association  
Dr. Gary Winchester, Florida Board of Medicine

**Advisory Board Members in Attendance:**

Sonya Albury, Health Council of South Florida  
Rev. Celillon Alteme, Tampa General Healthcare  
Dr. Lofty Basta, University of South Florida School of Medicine  
Kate Callahan, Huntington Research Group  
Dr. Domingo Gomez  
Ken Goodman, Forum for Bioethics and Philosophy  
Dr. Melissa A. Hardy, Pepper Institute on Aging and Public Policy  
Dr. David McGrew, American Academy of Hospice and Pain Medicine  
Ray Moseley, Forum for Bioethics and Philosophy  
Henry Pearson, Pearson's Rest Home  
Freida Travis, Department of Health, Bureau of Emergency Medical Services  
Dino Villani, Department of Health, Bureau of Emergency Medical Services  
Tanya Williams, Department of Health, Florida Board of Medicine

Meeting of the Working Groups: 9:20 - 10:00am

Meeting of the full Panel called to order at 10:15 am by Dr. Brooks.

1. Motion by Dr. Smith to accept the Minutes of the January 20<sup>th</sup> Meeting.  
2<sup>nd</sup> by Susan White.

**Motion passed unanimously.**

**Announcements.**

- Mention of recent press: Coverage of the Panel meeting in the Feb. 8 edition of the Ft. Lauderdale *Sun Sentinel* and the Feb. 21 edition of the *Tampa Tribune*.

- Lofty Basta described the contributions of *Project Grace*, its goals, and relevance to the Panel's work. The next meeting of the Project will be on April 24 , 8:30 am at the Tampa Marriott Hotel. Panel members are encouraged to maintain involvement in Project Grace, Dr. Basta was asked to keep the Panel informed of his progress.
- Samira Beckwith reported on EPEC, the American Medical Association's initiative in EOL care that provides a curriculum to educate physicians on care at the end of life. At the EPEC meeting she attended she saw a lot of interest in education in end of life care, and she thinks the EPEC format could be utilized for training nurses, social workers, etc.
- Dr. Smith was interviewed for 60 Minutes, which will air in 4-6 weeks.
- LuMarie Polivka-West said that HCFA was interested in tracking nutrition, hydration and pressure sores for patients in nursing homes.

**Report from the Financial and Regulatory Workgroup:**

Suggested that Panel require "two" MDs to determine capacity.

Noted the problem that, when a patient has advance directives, family members may disagree with the treatment decisions made by the patient. The doctor is caught in the middle. Perhaps deny payment for care that has been refused in Advance Directive.

*[Regulatory and Finance Working Group temporarily put on hold for a discussion about FS765 and advance directives.]*

**Report from the Advance Directives Workgroup:**

The group raised for discussion the possibility of reconsidering its position on the previously passed recommendation to remove the terminal illness clause from FS765 (p.20 of the Interim Report). The work group expressed its continued support for the deletion of the word "terminal" (wishes expressed when competent should carry over to when incapacitated), but raised the issue for the Panel to address. Would putting the word terminal back in and requiring the signature of only one physician be a reasonable compromise?

Jim Towey - restated the concerns he raised in his letter to the Panel, e.g., that this change would have far reaching consequences; that it requires extensive education, that he believes it places vulnerable groups at risk (such as the developmentally disabled); that he believes the Panel should take more time to discuss these issues- that members of the Florida Legislature do not understand advance directives.

Dr. McGrew - because of current ignorance on this issue (public and private) the changes cause by removing terminal will not be so sweeping. The terminal illness clause is ignored anyway. A person has the right to choose their health care when capacitated. Becoming incapacitated should not change that right.

P.K. Jameson - noted that the Legislature has had exposure to advance directives in Florida. The Dept. of Elder Affairs has held at least 24 forums on advance directives around the state and at least one legislator was present at each, so there has been exposure.

Dr. Gomez - (in response to Jim Towey's concerns about what removing terminal will do to the poor and minority groups). Noted that he has had experience working with the

poor and minority groups in Florida and that they do know what they want for their care and what they would like their care to be like at the end of life. Poverty does not reduce a person's capacity to make decisions about their care.

Cathy Emmett - expressed concern that all seems to boil down to whether or not to take terminal out. There are other facets to the Panel's work that we shouldn't lose sight of.

Dr. McGrew - because we have taken testimony that the terminal clause is a public problem, we are responsible if we do not respond and do not make a change, or delay making a change to something we have identified as a problem.

Dr. Brooks invited a motion to delete this recommendation.

2. Mr. Towey indicated that he would be interested in making such a motion, if someone would second it.

No second was offered.

Break for lunch, 1:00 - 1:45pm.

Next meeting was set for Monday, March 22 in Orlando, site to be determined.

On behalf of the Panel, Dr. Brooks thanked Mary Labyak for making arrangements for the February 24<sup>th</sup> meeting. Ms. Labyak said that Marriott had been very generous.

Discussion was raised about establishing a formal mechanism for the Panel to deal with press related issues. Ideas were to get a series on EOL care in the news media i.e. N-PR, etc., meet with editorial boards, have Panel members and attendees commit to informing their constituencies, have a formal press conference at the Capital to talk about the Panel and the issues before the Bill comes before the Legislature.

3. A motion was raised (Susan Acker) to appoint a small working group to help with publicity and getting the issues out in a consistent manner. Motion received a 2<sup>nd</sup> and passed.

Volunteers for the new work group were:

Susan Acker, Kate Callahan, Samira Beckwith, and Dr. Smith.

A suggestion was made to add a public relations person to the Advisory Board. The new working group should make a recommendation for the new advisor.

### **Report from the Pain Management Workgroup**

Identified ways to inform physicians about pain management and guidelines in Florida:

- Place an insert in the annual license renewal form (Sept./Oct.).
- Laminated vital sign care, pain as 5<sup>th</sup> vital sign.
- Develop a continuing education/ reference CD ROM.
- Look at what other states are doing; Oregon has a resource directory on a website; would this be practical in FL? Maryland has a hotline physicians can call with questions about pain management at end of life. It has been in operation 1 year, with funding from pharmaceutical companies,



- Patient education speakers in end-of-life care. Target the Hispanic population.
- Recommend to the Board of Medicine that they recognize palliative care certification...

Dr. Brooks - suggested that there could be a hotline for patients like the one run by the American Cancer Association.

Sonya Albury - pointed out that AHCA has a web site in development now, and that we could pass on our concerns to them. There is also a demonstration of an HIV/AIDS CD now, and there is also one on diabetes in development. We could establish a public/private partnership for an EOL CD.

General discussion regarding advance directives.

Meeting adjourned at 4:30pm.

**Minutes of The Panel for the Study of End-of-Life Care**  
**Monday, March 22<sup>nd</sup>, 1999**  
**The Hurston Building, South Tower Orlando, FL**

**Panel Members in Attendance:**

Rev. Celillon Alteme, Tampa General Healthcare  
Samira Beckwith, Hope Hospice and Palliative Care  
Dr. Bob Brooks, Secretary, Florida Department of Health, alternate for Dr. Panzer  
Marie Cowart, Pepper Institute on Aging and Public Policy  
Cathy Emmett, Florida Nurses Association  
Lori Daiello, for Joan Fulbright, Association of Community Hospitals and Health Systems of Florida Inc.  
Stan Godleski, Consumer Advocate  
Meta Caulder, for Gema G. Hernandez, Department of Elder Affairs  
Pete Buigas, Agency for Health Care Administration  
Mary Labyak, Hospice of Florida Suncoast  
LuMarie Polivka-West, Florida Health Care Association  
Ken Rubin, The Florida Bar  
Marshall Seiden, Florida Association of Homes for the Aging  
Tanya Williams, alternate for Dr. Gary Winchester, Florida Board of Medicine

**Advisory Board Members in Attendance:**

Amanda Hopkins-Alexiadis, for Sonya Albury, Health Council of South Florida  
Kate Callahan, Huntington Research Group  
Ray Moseley, for Ken Goodman, Forum for Bioethics and Philosophy  
Jane Hendricks, Attorney at Law  
Dr. David McGrew, American Academy of Hospice and Pain Medicine  
Henry Pearson, Pearson's Rest Home  
Freida Travis, Department of Health Bureau of Emergency Medical Services

Dr. Melissa A. Hardy, Pepper Institute on Aging and Public Policy  
Dr. Robbie Roberts, AHCA (Tallahassee, FL)

Meeting called to order @ 10a.m.

1. Motion by Kate Callahan to approve the Minutes from the 2/24 meeting.  
2<sup>nd</sup> by Pete Buigas

Amendment by LuMarie Polivka-West:

page 2, under the topic of Advance Directives (after the 1<sup>st</sup> sentence):  
add: "...in case there was a need for an alternative position."

Amendment passed

**Motion passed**

Next meeting:

- ↳ With legislative hearings, the Panel agrees to forgo an April meeting in favor of a later meeting.
- ↳ The Panel agrees to have a meeting on Friday, May 21<sup>st</sup> in Orlando, FL

2. Motion by Stan Godleski for the next Panel meeting to be set for Friday, May 21<sup>st</sup> in Orlando, FL.

2<sup>nd</sup> by Dr. Cowart

**Motion passed**

Status of the Panel Bill:

(The Panel bill and all amendments made thus-far, handed out to the Panel. Dr. Brooks had submitted bill (HB343) which was then taken up by the Elder Affairs and Long Term Care Committee, currently chaired by Rep. Nancy Argenziano. Senator Klein as a companion bill in the Senate)

- ↳ The Bill (based upon the Panel's recommendations set-forth in the Panel's Interim Report) passed the Elder Affairs Committee (House Committee) 9-0
- ↳ The Bill (the Senate version) will now go in front of the Health, Aging, and Long-Term Care Committee (Senate Committee).

Dr. Brooks read through the Bill as it now stands, highlighting the amendments made by the House Committee. Each topic was presented to the panel and discussed by the Panel.

Dr. Brooks noted that Representative Greenstein has introduced a separate bill to test Smart-Card technology in the area of advance directives.

In addition to the "terminal" issue, other issues that seem to be problematic include the definition of persistent vegetative state and the continuation of the Panel and its work.. Using pain as a 5<sup>th</sup> vital sign, the portability of forms, the pilot projects and the DNRO issues seem much less problematic.

The Panel discussed including somewhat different intention language.

3. Motion by Mary Labyak to recommend that another panel recommendation be that health-care providers adopt standards.

2<sup>nd</sup> by Ken Rubin

Motion to be read as follows: "The Florida Legislature encourages all providers to adopt standards for ensuring quality ... to respect and honor the person's wishes ... at the end-of-life."

(motion made in reference to line 12 of bill)

**Motion passed**

Ray Moseley made a case for the specific uses of ethics committees. They should be consulted when disagreements or ambiguities arise.

Cathy Emmett suggested we think about these changes for the panel's next set of recommendations.

Jane Hendricks agreed.

Dr. Brooks handed over the chair to Dr. Cowart, Vice-chair. (Dr. Brooks left the room.)

Kate noted that the educational component was not highlighted and that the panel should aggressively focus on educational issues in its next report.

Freida Travis agreed with the need to develop some training programs.

Panel members expressed a desire to continue to broaden the scope of their work and their recommendations. Mary Labyak lamented that the Panel's first set of recommendations had been reduced to a few specific issues, but the overall culture of end of life care had not really been addressed. She said that she hoped the Panel would be able to take a more comprehensive approach as it continued its deliberations, and recommend ways in which improved care could be provided in many different settings. It is important to develop a philosophy of care that is both compassionate and sensitive to the needs of individual patients. This overall philosophy must respect patient preferences, their relationship with their families and with their church, and it must also occur in an overall atmosphere of compassionate patient-centered care. Treating disease is often not the same thing as treating patients. We need to recognize that this difference can be particularly troublesome at the end of life, when patients and their families must come to terms not only with physical limitations but with their own mortality. Addressing these issues requires more than a single piece of legislation or a change in regulation. It requires changing the way we think about health care in our society.

Panel breaks for Lunch @ 12p.m. Reconvenes @ 12:30p.m.

Dr. Cowart handed the chair back to Dr. Brooks.

LuMarie Polivka-West announced that Florida Health Care Association planned to appoint Joe Krieger

4. Motion by Rev. Alteme to recommend that a representative from the Florida Developmental Disabilities Council be asked to join the Advisory Board Committee.

2<sup>nd</sup> by Marshall Seiden

**Motion Passed**

#### Pain Management/Palliative Care:

Topics of discussion:

- Federal guidelines of medical boards in the U.S.
- Mail-out in the Fall to all physicians, updating current positions and informing about changes and possible changes to standards of practice
- Web-site containing information pertaining to end-of-life care
- Educational standpoint: Educating physicians and providers on standards of practice and end-of-life care issues is needed
- Develop a "pain" hotline as a pilot program to demonstrate the utility of having experts in pain management available to answer questions on an emergency basis.

#### Advance Directives:

Topics of discussion:

- DNRO articles
- Educational standpoint: "Establish a community-based public education program about advance directives and end-of-life decision making with a cultural and ethnic sensitivity."

Ideas as to how to provide consumer education and education to health care providers on advance directives were discussed. Workshops in individual hospitals, churches, through AARP, through DOEA, and through EMS were all mentioned as avenues to continue to develop.

Rev. Alteme argued that we needed to be concerned with the general issues initially. Then let specific groups get together to discuss applications to their particular circumstances.

Dr. Brooks suggested the use of public service announcements.

Stan Godleski suggested that pastors incorporate these issues into their sermons; teach the pastors the information and let them educate their congregations.

Tanya suggested we form a coalition; gain strength; figure out how to accomplish it at a local level. AARP could provide widespread dissemination through the print medium.

Cathy argued that a coalition is important because the basic point is to get the information out to the community.

Stan Godleski suggested we look into using the SHINE network.

Dr. Brooks noted that we have 67 county health departments.

Kate Callahan suggested that we set up a sheet with bullet point that guides all these educational initiatives so the correct message gets relayed.

Cathy agreed that points that would guide the trainers--train the trainers--and then let them carry the message.

LuMarie noted that DOEA had contracted with Margaret Lynn Dugger and associates to develop a training booklet. That approach could be a useful starting point. Remembering Ariella Rodriguez' point that death is a taboo subject in certain ethnic communities, we need advice as to how to broach these topics in different communities.

Finally Panel members discussed how to take this message into the high schools--perhaps through the antismoking campaign.

Mary Labyak noted that this message about advance directives may be poorly received if it comes from an organization that people already view with suspicion.

Dr. Brooks noted that we need to train the trainers--develop the programs, and then monitor its effectiveness.

Questions about the August report were tabled until the May meeting when we will know what was passed. Then the Panel can decide how to take the next step.

Again group members noted their desire to say more than what was in the current bill, which contains no overarching statement of what good end of life care is or that it needs to be embraced by all providers. We need to also address people's fear; we need a

statement that this group's work involves more than particular practices, but that these practices develop from and are consistent with an overarching perspective on quality end of life care. A general philosophy on good EOL care would include the importance of self determination, the need for carefully developed provider-based programs; the need for ethics committees to be an integrated part of resolving difficult situations; the development of an underlying philosophy that would motivate care regimens; a protocol for reflecting on the issues of everyday care as well as the atypical cases; instructions about how to set up ethics committees and how to use them effectively; how facilities can develop care practices that are more patient centered; and how financing can be rethought so that good EOL care (and the associated training) can be reimbursed.

Samira noted that we have still been able to look only at the tip of the iceberg. She noted that the public relations subcommittee discussed developing a shared set of materials so that the Panel can distributed up to date, correct, and consistent information on EOL issues and practices.

(The Panel discussed Public Relational issues.)

Dr. Brooks handed over the chair to Dr. Melissa Hardy. (Dr. Brooks left the room.)

The panel discussed aspects of the political process; listings of the leadership of both the house and the senate were distributed. Members were encouraged to direct their thoughts to the Governor and to the leadership in order to counter some of the negative accounts that had been presented. Members were reminded of the web-site that contained somewhat current information on the bills, and Melissa agreed that the Pepper Institute on Aging would try to provide periodic updates on the bill's progress and the changes in language that were being incorporated.

Given that eliminating "terminal" as a barrier was expected to be a problem in gaining approval of the bill, the panel discussed possible compromise positions. Panel members agreed that they would reluctantly accept reinstatement of terminal, but rather than having the diagnosis of two physicians required, they argued that such determination should be left in the hands of the attending physician who could seek outside consultation if he or she deemed it necessary. Given that this would only apply in circumstances where advance directives had been completed, the requirement of a second physician was viewed as an unnecessary and, for certain facilities, a particularly problematic additional barrier to patient self determination. In addition, the Panel members said that continuation of the Panel and its work would be an important aspect of the bill if terminal were reinstated, since it would give the panel another opportunity to address this issue.

Panel adjourned @ 4p.m.

**Minutes of The Panel for the Study of End-of-Life Care**  
**Friday, May 21<sup>st</sup>, 1999**  
**The Hurston Building, South Tower Orlando, FL**

**Panel Members in Attendance:**

Rev. Celillon Alteme, Tampa General Healthcare  
Samira Beckwith, Hope Hospice and Palliative Care  
Dr. Bob Brooks, Secretary, Florida Department of Health, alternate for Dr. Panzer  
Susan Acker, for Pete Buigas, Agency for Health Care Administration  
Cathy Emmett, Florida Nurses Association  
Joan Fulbright, Association of Community Hospitals and Health Systems of Florida Inc.  
Stan Godleski, Consumer Advocate  
Jack Gordon, Hospice Foundation of America  
Meta Caulder, for Gema G. Hernandez, Department of Elder Affairs  
The Honorable Ron Klein, Florida Senate  
Kelly Skidmore, for The Honorable Ron Klein, Florida Senate  
LuMarie Polivka-West, Florida Health Care Association  
Ken Rubin, The Florida Bar  
Marshall Seiden, Florida Association of Homes for the Aging  
Molly McKinstry, Florida Association of Homes for the Aging  
Dr. Howard Tuch, Genesis ElderCare  
Dr. Susan White, Florida Hospital Association  
Dr. Gary Winchester, Florida Board of Medicine

**Advisory Board Members in Attendance:**

Sonya Albury, Health Council of South Florida  
Kate Callahan, Huntington Research Group  
Dr. Christiane Guignard, Agency for Health Care Administration  
Jane Hendricks, Attorney at Law  
Joseph Krieger, Florida Developmental Disabilities Council, Inc.  
Rev. Marilyn Mayse  
Dr. Mike McCarron, Florida Catholic Conference  
Dr. David McGrew, American Academy of Hospice and Pain Medicine  
Freida Travis, Department of Health Bureau of Emergency Medical Services  
Dino Villani, Department of Health Bureau of Emergency Medical Services

Dr. Melissa A. Hardy, Pepper Institute on Aging and Public Policy

Meeting called to order @ 10am.

Dr. Shea introduced to the Panel.

1. Motion by Samira Beckwith to approve the Minutes from the 3/22 meeting.  
2<sup>nd</sup> by Cathy Emmett

**Motion passed**

Next meeting:

☞ The Panel agrees to have two (2) more meetings before the August 1 due date for the Final Report.

↳ The Panel tentatively agrees to have meetings the weeks of Monday, June 21<sup>st</sup> and Friday, July 16<sup>th</sup>; both in Orlando, FL

Status of the Panel Bill:

Dr. Brooks recognized the hard work and leadership provided by Rep. Argenziano and Senator Klein in moving the EOL bill through both houses.

The House version of the Bill was carried through the Elder Affairs and Long-Term Care Committee by Representative Argenziano. This version of the Bill died on the House calendar. The House voted on the Senate version of the bill.

The Senate version of the Bill, carried through the Health, Aging, and Long-Term Care Committee by Senator Klein. This version of the Bill mirrored the House version and passed and has been given to Governor Bush to sign. It does not contain language for the continuation of the Panel for the Study of End-of-Life Care.

Dr. Brooks mentioned that the Dept. of Health has requested pilot projects on issues of advance directives and DNROs (for example). Freida Travis and Dino Villani (both Advisory Board members on the Panel) will be assisting Dr. Brooks with the development of such projects -- see also, SB 2228, page 5, lines 3-15.

In the wording of the Bill -- SB 2228, page 12, lines 1-10 -- Dr. Brooks noted that it asks for the Dept. of Health to work together with the Dept. of Elder Affairs to set-up a working group on issues of advance directives and DNROs (for example) -- see also, SB 2228, page 32, lines 22-28.

Other Outcomes of the Panel:

Marshall Seiden mentioned that he and Mary Labyak have developed a new spin-off of an existing Hospice Program which will be called the "Toby Wineman Jewish Hospice Program." It is a cooperative venture between Florida SunCoast and Menorah Manor. Initial funding of \$250,000 will be used to fund services in the Tampa Bay Area.

Samira Beckwith mentioned a grant proposal that Hope Hospice and Palliative Care has asked the RWJ Foundation to fund -- \$450,000 over three (3) years. The grant will bring together Florida Hospices and Palliative Care, Dept. of Health, Dept. of Elder Affairs, and the University of Florida to work together with members of this Panel on issues of end-of-life care. Bill Allen mentioned the desire for this proposed group to continue the type of work that this Panel has started.

Dr. Brooks mentioned that the American College of Physicians through the "Annals of Internal Medicine" is publishing a series of articles on end-of-life care.

Bill Allen reported that UF Medical school is implementing a new option by allowing 4<sup>th</sup> year students to rotate through hospice as an elective.

Dr. Brooks read through the Bill as it now stands -- SB 2228.

↳ Noted the recognition of the Panel's work in the Bill and the importance of the findings that the Panel has made concerning issues of advance directives, pain management and palliative care, etc -- pages 3-5, lines 22(3)-25(5).



- ↳ Sen. Klein noted the hard work that Dr. Brooks put in to see this Bill through and that there is definitely a need for education on issues such as those handled by the Panel -- page 5, lines 16-25.
- ↳ Noted the helpful language in the Bill for implementation of issues such as advance directives (for example) -- page 4, lines 19-28.

The following is in reference to Chapters 395, 400-401:

- ↳ Noted the new language related to the “withholding or withdrawing of cardiopulmonary resuscitation” -- pages 5-12.

The following are in reference to Chapter 765:

- ↳ Noted the new language related to “terminal illness” -- pages 17-18, lines 30(17)-4(18). This definition applies to the conditions required to enact a living will or advance directive.
- ↳ The inclusion of "end stage condition" will have to be clarified
- ↳ Persistent vegetative state has now been extracted as a separate condition

Break for Lunch @ 12pm. Reconvene @ 12:30pm.

Dr. Brooks continued to read through the Bill as it now stands -- SB 2228.

The following are in reference to Chapter 765:

- ↳ Dr. McCarron noted that it would be wise to find some language, on the issue of “terminal illness,” that was understandable across the board. The adoption of the “end-stage” language in the Bill was a compromise -- page 17, line 30. Dr. McCarron also noted the issues of “life-prolonging procedure” -- page 19, line 9; and “persistent vegetative state” -- page 19, line 29. He noted that the Panel’s work is a “positive” step forward and that the type of work that this Panel has done is worth continuing.
- ↳ Noted the Florida Developmental Disabilities Council and the new language related to person’s who never had the capacity dealing with the “withholding or withdrawal of life-prolonging procedures” -- page 23, lines 7-10.
- ↳ Noted the new language related to the concept of a “traveling” DNRO -- page 23, lines 22-27.
- ↳ Noted the new language related to the “procedure for making a living will, the addition of incapacitation, end-state, persistent vegetative state” -- page 25, lines 19-30. Also the addition of the same new language in the suggested living will -- page 26, lines 6-15.
- ↳ Questions about the suggested living will arose concerning what the implications are of signing one or all of the possible “(initial)” areas -- page 26, lines 12-14.
- ↳ Noted the new language related to the “procedure for enacting a living will” -- pages 27-28, lines 29(27)-9(28).
- ↳ Noted the new language related to the procedure in absence of a living will -- page 28, lines 13-29.

- ☞ Noted the language related to the “transfer of a patient” -- page 29, lines 16-25.
- ☞ Noted the new language related to the “proxy” -- page 31, lines 7-18.
- ☞ Noted the new language related to the term “persistent vegetative state” -- pages 31-32, lines 21(31)-21(32). Also noted the addition of the use of the Florida Bio-Ethics Network in reviewing cases of patients in a persistent vegetative state -- page 32, lines 4-21.
- ☞ Noted that under the new law, DNROs are medical procedures, not advance directives; McCarron asked why the family was not involved in making DNRO decisions; Dr. Tuch replied that decisions about medical procedures are between the physician and the patient and implemented by physician order.
- ☞ The requirement that 2 physicians be required to sign DNROs was raised. Mike McCarron argued that requiring two signatures was a protection; Bill Allen asked if there was any evidence that it has operated as a protection. There is considerable evidence that it acts as a burden. No one could provide any evidence of the former.
- ☞ LuMarie Polivka-West asked if the Panel could consider substituting another professional for the second physician, since obtaining signatures of two physicians is very difficult in certain health care setting.
- ☞ Questions were raised about the inclusion of "mentally and physically incapacitated" language; Meta Calder stated that this was a glitch in the bill, that the mentally and physically incapacitated language was included when terminal had been deleted. When terminal was reinstated, the mentally and physically incapacitated language should have been removed, but it was inadvertently retained.
- ☞ Mike McCarron stated his willingness to continue to work the Panel to develop mutually agreeable recommendations for the 2000 Florida Legislature.

2. Motion by Marshall Seiden for the next Panel meetings to be set for Monday, June 21<sup>st</sup> and Friday, July 16<sup>th</sup>; both in Orlando, FL.  
 2<sup>nd</sup> by Joan Fulbright

**Motion passed**

3. Motion of appreciation towards the Chair made by Susan Acker and 2<sup>nd</sup> by Marshall Seiden for all of Dr. Brooks' hard work.. He was commended for his leadership and congratulated for the successes of the Panel. Senator Klein noted that the progress that has been made on EOL issues was due to his leadership, and the success of the bill was due to his courage.

**Motion passed unanimously**

The Agenda for the next meeting will be focused around the Final Report due in August.

Panel adjourned @ 4pm.

**Minutes of The Panel for the Study of End-of-Life Care**  
**Monday, June 21<sup>st</sup>, 1999**  
**The Hurston Building, South Tower Orlando, FL**

**Panel Members in Attendance:**

Rev. Celillon Alteme, Tampa General Healthcare  
Samira Beckwith, Hope Hospice and Palliative Care  
Dr. Bob Brooks, Secretary, Florida Department of Health, alternate for Dr. Panzer  
Dr. Marie E. Cowart, Florida State University  
Cathy Emmett, Florida Nurses Association  
Joan Fulbright, Association of Community Hospitals and Health Systems of Florida, Inc.  
Meta Caulder, for Gema G. Hernandez, Department of Elder Affairs  
Stan Godleski, Consumer Advocate  
Mary Labyak, Hospice of Florida Suncoast  
Belita Moreton, Florida League of Health Systems  
Dr. Louis C. Murray, for Dr. Gary Winchester, Florida Board of Medicine  
LuMarie Polivka-West, Florida Health Care Association  
Ken Rubin, The Florida Bar  
Kelly Skidmore, for The Honorable Ron Klein, Florida Senate  
Dr. Alvin Smith, Oncologist, Florida Medical Association  
Dr. Howard Tuch, Genesis ElderCare  
Dr. Susan White, Florida Hospital Association

**Advisory Board Members in Attendance:**

Kate Callahan, Huntington Research Group  
Dr. Domingo Gomez  
Rev. Marilyn Mayse  
Henry Pearson, Pearson's Rest Home  
Freida Travis, Department of Health Bureau of Emergency Medical Services  
Dino J. Villani, Department of Health Bureau of Emergency Medical Services  
Tanya Williams, Florida Board of Medicine

**Observers:**

Susan Lampman, Pepper Institute on Aging and Public Policy  
Bill Allen, University of Florida  
Randy Bryan, J.D., Goldsmith and Grout, PA.  
Dr. Henry McIntosh

Meeting called to order @ 10am.

1. Motion by Dr. Murray to accept the Minutes of the May 21<sup>st</sup> Meeting.  
2<sup>nd</sup> by Dr. Tuch

Motion passed unanimously.

Dr. Brooks announces that the bill was signed by Gov. Bush on June 11<sup>th</sup>; thanks all the panel and board members for their commitment and hard work. Final decisions for the final report - July 21<sup>st</sup>, some possibility for adjustment after that.

LuMarie Polivka-West introduces the article in *Provider* magazine on Florida's end of life advisory panel and Samira Beckwith informs panel members of the July 22<sup>nd</sup> "60 Minutes" program regarding hospice care.

**Financial/Regulatory Workgroup:**

Chair: LuMarie Polivka-West

LuMarie Polivka-West introduces Randy Bryan, J.D., with Goldsmith & Grout, to the group.

2. Motion by LuMarie Polivka-West on Recommendation #1.  
2<sup>nd</sup> by Mary Labyak.

**(#1) "that continuing education in end-of-life care may be substituted for any of the current mandatory continuing education requirements (when these requirements have been met in previous cycles) for professions that include but are not limited to, physicians, nurses, social workers, pharmacists, administrators of health care facilities, clergy and lawyers."**

**Motion passed unanimously.**

3. Motion by LuMarie Polivka-West on Recommendation #2.  
2<sup>nd</sup> by Joan Fulbright.

Discussion:

- LuMarie Polivka-West: Recommendation is that the legislature recommend that professional organizations representing the aforementioned groups develop strategies to promote and provide incentives for educational programs and training in end-of-life care. The recommendation #2 is what standardized curriculum or standardized component training developed by the state should be included in the final report. The regulatory workgroup members were concerned about two major points: 1) the one hour continuing education for end of life care is not to be just instruction on advance directives and the law but to address good end of life care practices; and 2) the original proposal recommended end of life care continuing education to substitute for both HIV/AIDS and domestic violence if the requirements for the training had been met in the provisions cycle.
- Dr. Brooks: Do you want to keep and broaden the original or existing programs or do you mean to substitute or replace them?
- Bill Allen: How specific and restricted it would be - quality control problem?
- Cathy Emmett: The Board has authority - we have already discussed that issue.
- Mary Labyak: It is supposed to be a curriculum of end of life care. It is not just any of details in end of life care. It is not restricted to single component.
- Dr. Smith: If you overly restrict it, that will kill the entire program.
- Mary Labyak: We are thinking about going as far as a core-bone structure or the program, not any further.
- Dr. Brooks: Who should be more specific, us or legislature - we can let the legislature work on more specific issues or we can come up with individual issues as group.

- Dr. Smith: What we really would like to do is to do the same as we do for other courses. It is hard for legislature or board to deal with it. We can come up with something we can take from there.

**(#2): “that the Legislature encourage the ongoing development of innovative end-of-life educational programs and standardized training for all health care providers.”**

**Motion passed unanimously.**

4. Motion by LuMarie Polivka-West on Recommendation #3.  
Second by Joan Fulbright.

Discussion:

- LuMarie Polivka-West: This is an additional recommendation from the working group - **“to encourage professional boards to include but not be limited to standardized components on end of life care, such as clinical and ethical decision making, pain management, advance directives, etc.”**
- Dr. Brooks: Do you go ahead and list suggestions from the members? We have so far pain management and palliative care, advance directives, DNRO, and living wills, hospice care, bereavement counseling, and clinical and ethical decision making.
- Kate Callahan: We could easily spend 1 hour for any one of those issues - how would we be able to fit everything in a single 1 hour program? Do we have longer time frame?
- Dr. Brooks: At this moment, we have 1 hour if substituting (or replacing) AIDS education.
- Samira Beckwith: The logical order is to start with what we need to learn to communicate with patients.
- Dr. Gomez: Many physicians find it hard to talk about decisions at end of life, and certainly obtaining communication skills would be helpful.
- Dr. McIntosh: We should not just talk about 1 hour course but have to talk about changing the attitudes. It is very crucial element in end of life care, but it is not coming from legislature or legislating effort.
- Dr. Brooks: It might help if we advise the boards what we are thinking about as a group.
- Dr. McIntosh: How about directing boards to draw more direct attention?
- LuMarie Polivka-West: How about rephrasing it as “to encourage medical professionals to standardize end of life components, emphasizing personal decision making and ethical decisions?”
- Dr. Tuch: I think the more specific we get, the less likely we can address other issues - we should remain broad and let them decide what to address.
- Dr. Brooks: How about rephrasing it as “should include, but not limited to” and then list the individual components, such as palliative care, clinical ethical decision making, DNRO, advance directives, pain management, as suggested from the members? Is that still broad enough?

**(#3): “to encourage professional boards to accept standardized care training, including, but not limited to: a.) pain management; b.) advance directives, DNRO, and living wills; c.) hospice care; d.) bereavement counseling; and e.) clinical and ethical decision making.”**

**Motion passed unanimously.**

Motion by LuMarie Polivka-West on Recommendation #4 (#3 in the Interim Report).  
2<sup>nd</sup> by Mary Labyak.

**(#4): “that the Legislature recommend that professional organizations representing the aforementioned groups develop strategies to promote and provide incentives for participation in end-of-life training and that these professional organizations incorporate end-of-life education in their on-going educational activities.”**

**Motion passed unanimously.**

Motion by LuMarie Polivka-West on Recommendation #5 (#4 in the Interim Report).  
2<sup>nd</sup> by Joan Fulbright.

Discussion:

- Dr. Brooks: If we can get data from all community colleges and nursing programs, we can get the real flavor of what’s going on in education regarding end of life care. Should we, as group, give something more specific?
- Kelly Skidmore: We want them to know what’s the best curriculum not only the existing programs within the state, but outside our state, nationally, and on an international basis. Why should we limit the scope only to Florida?
- Dr. Smith: The universities and colleges are very honest people and they want to change the system to the better way, but just have to do on their own way. We should not tell them what exactly they should do.
- Bill Allen: If we go too specific, people start resenting what’s in there rather than implementing them.
- Dr. Murray: All involved departments and units have to be exposed and it takes a lot of time and energy.
- LuMarie Polivka-West: The working group would like to think about the components and suggestions during the lunch break and we’ll present them right after lunch.

**Motion withdrawn; scheduled for discussion after the lunch break.**

5. Motion by LuMarie Polivka-West on recommendation #6 (#5 in the Interim Report).  
2<sup>nd</sup> by Joan Fulbright.

Discussion:

- LuMarie Polivka-West: Our recommendation #6, which is #5 in the Interim Report, stays as it is in the Interim Report.
- Samira Beckwith: Are we going to give them some sort of directions in final report - otherwise, we are not going anywhere...?
- LuMarie Polivka-West: We could do that - we can provide the examples and we encourage panel members and advisers to submit examples prior to July 16<sup>th</sup>.
- Samira Beckwith: So, can we agree on recommendation here and then come up with some examples and add to the recommendation in the next meeting to have them included in the final report?
- Dr. Brooks: We are now voting on the recommendation #6 in this meeting. The working group will come up with examples to be included in this recommendation by next meeting.

**(#6): “that the Legislature create incentives for health and elder care providers and for publicly accessible media such as the press and public radio and television designed to encourage public dialogue about advance directives and end-of-life care options. Incentives might take the form of citation in annual ratings for providers, private funding for public radio and television productions that reflect the multi-cultural diversity in our communities (add examples).”**

**Motion passed unanimously.**

Motion by LuMarie Polivka-West on recommendation #7 (#6 in the Interim Report).  
2<sup>nd</sup> by Joan Fulbright.

Discussion:

- LuMarie Polivka-West: We would like to change ‘encourages’ to ‘require’ in the statement - “that the legislature institute a legislative proposal that requires excellence in end of life care.”
- Tanya Williams: As a regulator, it gives me a heartburn. How would we define “excellence?”
- LuMarie Polivka-West: The Health Care Financing requires the “highest practicable level of care.” The state might be able to adopt that definition or concept. The intent was to set a statement of expectation of excellent care.
- Mary Labyak: I have some concerns, unless we have assurance what “excellence means”. Currently, we have no uniform standard for people to choose in palliative care. It could be dangerous.
- Kate Callahan: I feel that there will be difficulty to identify uniform standard of ‘excellence’ in end of life care.
- Joan Fulbright: Can a legislative body recognize end of life care?
- Dr. Brooks: Could “excellence” be the facilities that go beyond the minimum standard? If so...
- Dr. Smith: We can regulate care, but we cannot legislate care. It is impossible.
- Stan Godleski: But there should be some reward for facilities that provide excellent care.
- Joan Fulbright: How about rephrasing it as “the appropriate regulatory agency recognizes organizations and facilities licensed under Florida Chapter 400 and 395, programs that demonstrate excellence in end of life care” and something like, such programs are eligible or qualified for reward, for example, gold seals.
- Meta Calder: First of all, is gold seal criteria applicable for end of life care program?
- LuMarie Polivka-West: Yes - it seems to be pretty much applicable in that the new Quality Nursing Home Bill includes program criteria in the new Gold Seal Program for nursing homes.

**(#7): “that the appropriate regulatory agency recognizes, in facilities and organizations licensed under Florida Chapter 400 and Chapter 395, programs that demonstrate excellence in care at the end of life. Example of recognition might include end of life programs for inclusion in the Gold Seal Award for nursing homes.”**

**Motion passed unanimously.**

Break for Lunch. Reconvene.

6. Motion by LuMarie Polivka-West on Recommendation #11.  
2<sup>nd</sup> by Joan Fulbright.

**(#11): “that the Legislature establish a working group made up of a representative from the Florida Legislature, staff representation from the House and Senate Appropriations committees, the Agency for Health Care Administration, the Department of Elder Affairs, the Department of Health, and representatives from the respective provider associations to examine reimbursement methodologies for end-of-life care such as consultative hospice service and a Medicaid case-mix reimbursement of palliative care, and to develop recommendations for incentives for appropriate end-of-life care and enable all providers along the health-care continuum to participate in an excellent standard of end-of-life care.”**

**Motion passed unanimously.**

7. Motion by LuMarie Polivka-West on revised Recommendation #5 (#4 in the Interim Report).  
2<sup>nd</sup> by Joan Fulbright.

**(#5): “that the chancellor of the state university system’s work group on end-of-life curriculum survey include a review of required health care texts and classroom instruction for inclusion of pain and palliative care instruction and clinical and ethical decision making in end-of-life care and make recommendations for basic end of life curriculum through the respective Boards of medicine, nursing, social work, pharmacy, and other health care disciplines.”**

**Motion passed unanimously.**

LuMarie Polivka-West: We will develop the excellence in care issues we presented in the morning and add to the group’s recommendations at the next meeting (for the final report). A final note is the discussion we had on requiring health plans and insurance companies to give information on advance directives and end of life care to all beneficiaries upon enrollment. It is an area in need of future consideration.

**Pain Management/ Palliative Care Workgroup:**

Chair: Dr. Howard Tuch

8. Motion by Dr. Tuch on Recommendation #1.  
2<sup>nd</sup> by Dr. Murray.

Discussion:

- Dr. Tuch: Our recommendation #1 states that “the Panel of End-of-Life Care believes that all persons should have access to effective pain management and palliative care services.” We should specifically amend the Patient Bill of Rights to include a right related to pain management and palliative care. The initial discussion we had was whether or not palliative care was a right, since there are concerns about litigation. But as we discussed, the inclusion of a right to access to a palliative care within the Patient Bill of Rights may not imply any specific liability to providers. A part of the recommendation of our working group would be strengthening it which suggests that



we include specific reference to pain management and palliative care in the context of the Patient Bill of Rights.

- Tanya Williams: Sometimes when we talk about this issue, we want to talk about in the context of nursing homes, under the nursing home statute areas, liability issues, such as violating the patients' rights, but under the patients' rights statutes, which is 381, includes similar kinds of civil suites provisions or enforcement provisions about the Patient Bill of Right. Other than being required to tell patients what their rights are, there isn't any penalties for violating patients' right. Chapter 381 is a soft statute.
- Dr. Brooks: Is this really any different or even broader that LuMarie has just suggested as a recommendation not to be voted on a motion, in essence requiring HMOs, insurance companies, hospitals, and nursing homes to include information on end of life care to their patients or clients?
- Tanya Williams: Right now, every physician and hospital are to be given a written document and tells them what their rights are and it has been a law for several years. So, this is a recommendation to go into the statute and revise the content of the Bill of Rights to speak to the end of life, when doctors give it to you, in a little documents that you take home and read, every something should be in there. Doctors offices and hospitals should make it available.
- Dr. Brooks: Are we recommending that legislature add it as a requirement, not without specifying the exact wording what will have to be in the document or do we have the actual document that has to be included?
- Dr. Tuch: We have not worked on direct language, but recommend to amend the current Bill of Rights with specific reference to pain and palliative care.
- Dr. Brooks: Are your recommendations including end of life issues as well as pain and palliative care?
- Dr. Tuch: We can talk about what is the distinction between palliative care and end of life care and in our next recommendation, we would like to adopt what is palliative care.

**(#1): "All persons should have access to effective pain management and palliative care services and we recommend the legislature amend of the current Patient Bill of Rights to include specific reference to access to pain and palliative care."**

**Motion passed unanimously.**

9. Motion by Dr. Tuch on Recommendation #2.  
2<sup>nd</sup> by Dr. Murray.

Discussion:

- Dr. Tuch: Our next recommendation provides the definition, of "palliative care." It used to be equal as 'hospice' but it is changing. It is a part of our obligation to define what "palliative care" means. We need to say, as a panel, to the legislature what we mean by "palliative care." We recommend to adopt the World health Organization's definition that "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 possible quality of life for patients and their families." The definition printed here is most commonly used and helpful for people to understand what palliative care means.

- Tanya Williams: Do we need to clarify who should be adopting the definition? The recommendation just says ‘adopting’ but should the panel be adopting, or should legislature be putting somewhere in law, or should the regulating agencies be adopting in terms of regulating? Who do we think should be adopting?
- Dr. Gomez: Can we just say we are recommending this? There is one area in here that states pretty open to interpretation. Maybe this is something we might want to recommend in order to prevent people from being subjective to very invasive treatment.
- Dr. Tuch: Other than broad terms to say that people should have access to pain management, I am not sure it is our job to define what...
- Samira Beckwith: Is this recommendation to be adopted by legislature as the definition of palliative care?
- Cathy Emmett: If we can make it as broad as possible. I see palliative care all over, but it does not necessarily mean this definition.
- Dr. Smith: I would suggest that we combine the definition written Patient Bill of Rights proposal and leave it there. That’s probably easier way to do.
- Dr. Tuch: Right now, let’s at least try to get a consensus what it is and I would suggest legislature should adopt it as a standard definition of palliative care.
- Dr. Smith: I think one problem brought up here is an enforcement problem.
- Dr. Tuch: You are right, but we do not need to go there right now. Our motion still stands that the Florida legislature should adopt the World Health Organization’s definition.
- Kelly Skidmore: Maybe you can state it in your first recommendation, as “all persons should have access to effective pain management and palliative care services defined by World Health Organization. And then in statute, 381, you are not having specific definition.
- Meta Calder: I have a trouble for the definition itself. I did not know that you can only choose palliative care if it is not responsive to curative treatment. Can’t it be selective?
- Dr. Tuch: The definition by WHO does not mean that you do not have access to the clinical protocols, it just means that the system of palliative care is designed to the patients whose disease is not responsive to curative treatment.
- Dr. Smith: I think her question is good. If you do not have terminal condition, or end stage condition, you decide not to, and you decide you are going to starve to death, I think that’s right. Can you have palliative care under that right.
- Tanya Williams: You said there were several definitions. What are others?
- Dr. Tuch: There are some others, but they embrace the same concept. And the World Health Organization’s is certainly the most widely accepted.
- Kelly Skidmore: When do they use the definition?
- Dr. Brooks: If you need to pick the definition for something you have to do in the future, setting up the new rules, or new gold seal program or whatever it is, and if this is the definition that the Panel is recommending to use, I think it lends itself to be picked off the tree if they need it in any number of situations.
- Kelly Skidmore: But if it is not in the statute, how would we say this is what we meant. If we do not put it in the statute, how would we recognize that is what the legislature is going by?
- Meta Calder: What you can say whatever you want to say in the Bill of Rights and you just add the sentence right after what palliative care means right in the Bill of Rights.

- Dr. Brooks: I would suggest you keep your motion as it is - so that whatever the future needs come up, they can see the Panel with all expertise recommends this definition to be used.

**(#2): “Legislature adopt the definition of palliative care according to the World Health Organization: ‘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 possible quality of life for patients and their families.’”**

**Motion passed unanimously.**

10. Motion by Dr. Tuch to re-consider the wording of Recommendation #1.  
2<sup>nd</sup> by Dr. Smith.

Discussion:

- Dr. Brooks: It was suggested by Kelly that we add the World Health Organization’s definition of palliative care in recommendation #1, as “all persons should have access to effective pain management and palliative care services defined by World Health Organization”

**(#1) (rephrased): “All persons should have access to effective pain management and palliative care services, as defined by World Health Organization, and we recommend legislature to amendment of the current Patient Bill of Rights to include specific reference to access to pain and palliative care.”**

**Motion passed unanimously.**

11. Motion by Dr. Tuch on Recommendation #3.  
2<sup>nd</sup> by Dr. Smith.

**(#3): “Health care facilities, other organizations, and providers caring for people at the end of life should develop strategies to provide access to palliative care. Standards for pain management, management of other distressing clinical symptoms at the end-of-life, advance care planing, and systems to attend to emotional and spiritual needs should be in palace or available in all settings which care for seriously ill patients.”**

**Motion passed unanimously.**

12. Motion by Dr. Tuch for Recommendation #4.  
2<sup>nd</sup> by Dr. Murray.

Discussion:

- Dr. Tuch: There is an increasing effort within some of the agencies to monitor the implementation of palliative care and strategies. The concern is that if we direct those agencies to adopt set standards with absence of time to educate their own facilities to provide good palliative care services embracing these definitions, we may put in place regulatory processes that are more punitive than educational. There may

not be adequate existing knowledge of data to reasonably evaluate palliative care. A part of the change we have begun to discuss within the working group was rather than adoption of standards that we recommend the monitoring systems for regulatory standards. There is a need to understand what the problems are in different health care settings with regard to the end of life care issues. So, changes are from oversight to data analysis and collection for understanding what the nature of end of life care is. It makes better sense to start with identifying the current problems and approaches rather than attempting to develop the set of standards while we do not truly understand what the current problems are.

- Dr. Brooks: It is not withdrawing the motion, but just changing in wording, such as “monitoring.” So, keeping after “such standards may includes...”, we focus on accumulating data what’s been than currently.
- Marie Cowart: It seems that whole notion of monitoring standards will be helpful to the dilemmas we have in our regulatory areas. On page 21 and 22, it talks about recognizing excellence in care and establishing curricula, and it seems to me that the standards provide the basis for two recommendation our work group has. So, having this recommendation lets us dismount the walls between the working groups and integrate our recommendations together. I think this recommendation for standards are wonderful.
- Kate Callahan: Those are the mechanisms to monitor pain and palliative care strategies. When you go down through each one of your points, you are really looking at the heart of the circular model, when you start the assessment all the way to the evaluation and the evaluation pushes you back into the assessment mode. So, it is really a circular thing and never stops. It is on-going.
- Dr. Tuch: If we try to embrace that concept, “The Agency for Health Care Administration and the Department of Elder Affairs should be directed to develop or adopt reasonable mechanisms to monitor the implementation and effectiveness of pain and palliative care strategies.” I like mechanisms or systems better than standards. Our concern is identifying the agencies that should be involved - there are other agencies that might be responsible. Do we have to be specific?
- Tanya Williams: Shouldn’t we include Department of Health? Agency of Health Care Administration is responsible for regulation for facilities we do not do that, we just do the service recommendations.
- Dr. Tuch: or the designated agency.
- Dr. Brooks: It depends on wording - who we are focusing on, are they meant to be looking at institutions, which was the original intent. If we are looking to make sure that the nursing homes, hospitals, and hospices have in place mechanisms that deal with palliative care, we are not the right group. We deal with the providers.
- Bill Allen: Why don’t we just say “appropriate state boards and agency’ and let others figure it out?
- Dr. Tuch: What agency would be appropriate for developing standard or monitoring system for end of life care for education projects?
- Dr. Brooks: It depends how you try to set the standards of care. I am not sure if we can do it here in regards to what are the standards of medical care. The only formal authority we have at the Department of Health is discipline through the boards. I think what you originally intended to is more institutional - when you put down the Agency and Department of Elder Affairs. But I do know how we can monitor physicians directly and individually - we only see them individually, not as a group - we do not set policies.

- Marie Cowart: Why don't we say "Agency for Health Care Administration and appropriate agencies..."
- Dr. Tuch: (rephrasing recommendation #4) "The Agency for Health Care Administration and appropriate agencies should be directed to develop or adopt reasonable mechanisms to monitor..."
- Dr. Tuch: We have discussed that it might be the easy way to do that, at least certain segments of health care, in long term care. We can look at a dozen of different variables on the MDs, and ask about pain management, advance directives, psycho-social support, etc. And not only that, with its existing data, it could be evaluated to monitor what's happening in state at least in this one segment of health care. For other data bases in hospitals and other institutions, we can ask what record they are keeping, and if pain management is not in there, we can recommend to include it.
- Dr. Brooks: It is more institutions. Then your wording would be appropriate that "the Agency of Health Care Administrations and other appropriate agencies..." Should be directed or encouraged?
- Dr. Tuch: We would say "directed."
- Mary Labyak: I wonder if you consider adding the DOEA back in? Because hospice rules are done by DOEA. What we are looking at is more like hospice than any other providers.
- Tanya Williams: There are some other issue areas in end of life care, such as for children in end of life care, etc, and there might be other agencies than the Agency for Health Are Administration that are experienced in death and dying areas.
- Dr. Brooks: How about "the Agency for Health Care Administration, the Department of Elder Affairs, and the Department of Health where appropriate, should be directed..."
- Susan White: When I read 'mechanisms' particularly in the hospital setting in terms of reporting, my concern in our perspective is that at this point, there is no collective standard and if it has to be developed, it is the additional burden. Want to make sure that it is not the intent of this statement.
- Dr. Tuch: They will do need develop it, but this recommendation is not necessarily requiring it.
- Kelly Skidmore: Those are not mechanisms, those are strategies to monitor the mechanisms. We should call it strategies, actions, approaches, tools, etc, something else.

**(#4): "The Agency for Health Care Administration, the Department of Elder Affairs, and the Department of Health where appropriate, should be directed to develop or adopt reasonable approaches to providing effective effectiveness of pain and palliative care strategies. Such strategies may include but not limited to:**

- a. Providing information regarding the options for care and support that exists within the local community.**
- b. Opportunity to participate in advance care planning and discussions of choices and decisions with appropriate providers.**
- c. Develop excellence in pain management and the management of other distressing symptoms at the end of life.**
- d. Review/redesign of organizational policies and procedures that may pose barriers to or promote effective palliative care.**
- e. Strategies to monitor and improve the effectiveness of pain management and organizational standards of end-of-life care.**

**f. interdisciplinary approaches to meet the social, emotional, spiritual, and bereavement concerns of people at the end-of-life and their families.**

**Motion passed unanimously.**

13. Motion by Dr. Tuch on Recommendation #5.  
2<sup>nd</sup> by Dr. Murray.

Discussion:

- Kelly Skidmore: Don't we have something like that in the bill?
- Dr. Brooks: We do have some protective language on line 21 through 28 on page 4, "...". The motion does comment on not promoting or condoning physician assisted suicide, which is maybe the only statement we have in this whole final report, probably a little more stronger, a little more specific, so the motion is worthy at least for consideration as separate entities, not exactly the same as the statute as in new bill.
- Cathy Emmett: We are not condoning physician assisted suicide and euthanasia, but I've heard some discussion during the legislative process that in some way this panel was trying to go down so slippery slope towards that. I think it is important to have some statements in there.
- Meta Calder: If I remember the statute, I think we've already had language like that.
- Bill Allen: Some people are against even doing this much, some people are again withholding or withdrawing treatment in the beginning, before any of these statutes in the past, and those people are going to accuse you no matter what you say. It seems to me that it gives them more reason to attack by specifically responding to it.
- Dr. Brooks: It is a little different from the new bill because it has a statement which is something we talked about before... "Paragraph from the new bill"
- Dr. Tuch: In final report, I'd like to be able to say standard medical care we are recommending is in fact affecting pain management.
- Bill Allen: May I suggest that we keep the physician assisted suicide, but take euthanasia out? Because according to the majority of literature, withholding or withdrawing is considered to be passive euthanasia, while physician assisted suicide is considered to be active euthanasia. So, it could create confusion.
- Dr. Brooks: I would suggest, if you are concerned about some technicalities, that we rather add some clarifying language, even put some parentheses.
- Dr. Smith: We don't interpret that way - it is conceptual differences. We only make decisions to treat or not to treat and we don't see it as in euthanasia.
- Cathy Emmett: On day-to-day practice basis, people use just the word euthanasia, but do not distinguish then as passive or active euthanasia.

**(#5): "Pain management to achieve acceptable comfort for people at the end of life, when provided in full compliance with the Chapter 30 "Intractable Pain Statute," should be construed as meeting the standard of medical care. Nothing in this recommendation should be taken to promote or condone physician assisted suicide or euthanasia."**

**Motion passed unanimously.**

14. Motion by Dr. Tuch on Recommendation #6.  
2<sup>nd</sup> by Dr. Murray.

Discussion:

- Dr. Tuch: We do not have any substantial changes in recommendation #6. This is in fact on-going. It is not in the bill, but we are already in the process that board of medicine is in process in doing this.

**(#6): “The Panel recognize that too many Floridians are dying without adequate pain management. To provide appropriate pain relief to patients, particularly patients at the end-of-life, we recommend that health-care boards adopt rules concerning guidelines for pain management. We also recommend that these boards develop and promote educational programs to disseminate information regarding these rules and practices.”**

**Motion passed unanimously.**

15. Motion by Dr. Tuch on Recommendation #7.  
2<sup>nd</sup> by Dr. Murray.

Discussion:

- Bill Allen: I like the idea of establishing a program on end-of-life care, but I don't see why we should designate it as Pepper Institute on Aging and Public Policy. Many of universities, including it University of West Florida, have population that is interested in end-of-life and others might be interested in making a proposal. I don't understand why we should pick up the Pepper Institute over any others.
- Dr. Brooks: So, you recommend we amend to broaden the recommendation to set standards may include one or more centers.
- Bill Allen: We don't think we should choose one. A bunch of people are doing this and have a bunch of stuff going on and some of them might be combined. I think designating one is too specific.
- Dr. Brooks: So, if I rephrase Dr. Tuch's motion as “establish a program on end-of-life care at one or more educational institutions to serve as centers of research and policy analysis in end of life care in the state. Would this amendment be fair?
- Marie Cowart: I think we mean “a center” in this recommendation as a midpoint and one of the functions that the Pepper Institute could serve is coordinating function which does involve the members in state university systems. Ten universities are in the system, so I think the word is put this way that the Pepper Institute is taking some coordinating leadership.
- Bill Allen: Even so, still why we should choose the Pepper Institute, why others might not be a midpoint?
- Dr. Smith: I think the Pepper Institute ought to be reconsidered, but I don't think the government should ever be franchising anybody...
- Dr. Tuch: We'd like to amend the motion as suggested.

**(#7): The Florida legislature should adopt language to promote the following recommendations:**

**Professional education:**

**a. encourage medical, nursing, social work, and pharmaceutical schools throughout the state to review and implement curricula designed to train providers in principles of pain management and palliative care.**

- b. encourage development of materials and courses designed to educate practicing health-care professionals on appropriate standards on pain management and palliative care.
- c. promote specialist training programs (palliative care fellowship program) for physicians in each of Florida's medical school.
- d. promote specialist training for nurses, nurse practitioners, pharmacists, social workers to create a cadre of palliative care specialists.
- e. promote increased and earlier referral to hospice programs for appropriate patients.
- f. establish programs on end-of-life care at one or more centers to serve as centers of research and policy analysis on end-of-life care in the state. Public education a and b as in the interim report.

**Public Education:**

- a. create a state-wide education campaign to improve understanding of palliative care, enhance access to hospice and palliative care services and to promote understanding of the need for advance care planing and advance directives.
- b. create culturally sensitive education programs to improve end-of-life care in minority communities.

**Motion passed unanimously.**

16. Motion by Dr. Tuch on Recommendation #8.  
2<sup>nd</sup> by Dr. Murray.

Discussion:

- Dr. Brooks: We'll need to discuss some specific demonstration program in the 7/16 meeting. If anyone has any ideas for effective demonstration programs, please present the proposals in the next meeting with the ideas how it is going to be funded. We'll need it to do this more formally to list in the recommendation for the department to consider.
- Freida Travis: It is fair that the Panel provide as much information as possible, such as the description of the program, funding source, purposes, etc.

**(#8): "The Florida Legislature should designate specific funding of studies to determine the clinical needs, costs, and services available to Floridians dying at home, hospice, hospital, assisted living centers, nursing homes, and those without health-care insurance."**

Motion passed unanimously.

**Advance Directives Working Group:**

Chair: Kate Callahan

17. Motion by Kate Callahan on Recommendation #1.  
2<sup>nd</sup> by Ken Rubin.

Discussion:

- Kate Callahan: We would like to change the recommendation, although it is still rather strongly stated. "We believe that every person in Florida has a constitutional



common law right to refuse medical treatment. This right extends to individuals who are currently not competent or do not have ability to refuse medical treatment. We oppose any barrier language including terminal condition and end stage condition in the statute 765 of 1999 as limitation of language as to person's rights. Each individual may exercise his or her right to define the conditions which by their advance directives should be honored. We therefore hold the recommendation that the Florida Legislature remove all the language barriers to execution of advance directive rights.

- Dr. Smith: Is that really constitutional?
- Ken Ruben: I have read it a hundred times and I am firmly convinced that it says you have a right to refuse medical treatment and that rights extend to people without capacity.
- Bill Allen: Person has a right to refuse medical treatment and Browning states that they do not lose that right by becoming incapacitated. But beyond that, you have to look into the specific cases and each case might be different - and there might be some exceptions for that general rule.
- Dr. Smith: Can I read out loud what the Senate Economic Impact Statement says? It says "the State Supreme Court has recognized four state interests which might on case by case basis overwrite the constitutional right with respect of health care decisions which would result in person's death - preservation of rights, protection of innocent third parties, prevention of suicide, and maintenance of ethics and integrity of medical profession." There are four things that we are working on for the medical association. How can we make doctors more comfortable under this situation, if it is so framed as it is now?
- Kate Callahan: It is the problem - it is not about the physicians, but it is about the patients. It has been about the physicians in some respect when it comes to the law. But it is really about the patients, how they feel and how their rights can be honored. It will be a struggle to educate people to a different paradigm of thought, but at some point, it has to occur.
- Dr. Smith: It is not what I see. There are some cases what are not straight forward. Every physician is willing to do exactly what their patients want, but many of them are only unwilling to do so because they are so frightened of the law. Physicians are not fighting this, they just don't know where they stand. So, I suggest the law remove all the terminal requirement and barrier language.
- Bill Allen: I agree with removing terminal condition requirements, but we also have to educate people to understand burden and benefit of quality of life.
- Tanya Williams: It is very important that we speak from compassion, but what we really need is a dispassionate legal ground where we can say we find it constitutional.
- Dr. Brooks: I understand we all agree the motion, but just from different perspectives and standpoints.

**(#1): "It is our belief that every person in Florida has a constitutional and common law right to refuse medical treatment. This right extends to individuals who are currently incompetent or do not have ability to refuse medical treatment. We oppose to any barrier language including terminal condition and new end stage condition language in 765 of 1999 as limitation language of person's rights. Each individual has and should exercise his or her right to define the conditions whereby their advance directives should be honored. It is our recommendation that Florida State Legislature remove from 765 all barrier language which prevents persons from implementing their advance directives."**

**Motion passed unanimously, with one abstention (Dr. Brooks).**

18. Motion by ? on Recommendation #2.  
2<sup>nd</sup> by Ken Rubin.

**(#2): “funding should be provided by the legislature (and private sources) for state agencies, professional societies, universities, community colleges, and civic organizations to educate consumers, the public, and health care providers about how to implement these individual rights with appropriate cultural awareness in order to facilitate the recognition and implementation of these rights.”**

**Motion passed unanimously.**

19. Motion by Kate Callahan on Recommendation #3 (#2 in the Interim Report).  
2<sup>nd</sup> by Ken Rubin.

**(#3): “Recommend that the legislature create a standardized and portable DNRO form that can be used in all patient settings. Create policy and procedures to implement the effective use of this form.”**

**Motion passed unanimously.**

20. Motion by Kate Callahan on Recommendation #3 (additional).  
2<sup>nd</sup> by Marie Cowart.

Discussion:

- Kate Callahan: “The terms mentally and physically incapacitated were added to the new legislation when terminal was expected to be removed. Since terminal is left in the statute, this phrase is we now believe inappropriate. Therefore, we recommend that terms mentally and physically incapacitated be deleted from the statute 765.”
- Dr. Brooks: Let’s look at page 28, line 25. I understand if you do not specifically say physically incapacitated, incapacitated generally means mentally incapacitated. So, the recommendation is to remove mentally and physically and just state incapacitated.

**(#3) (additional): “The terms mentally and physically incapacitated were added to the new legislation when terminal was expected to be removed. Since terminal is left in the statute, this phrase is we now believe inappropriate. Therefore, we recommend that terms mentally and physically be deleted from the statute 765.”**

**Motion passed unanimously.**

21. Motion by Dr. Smith on Recommendation #4.  
2<sup>nd</sup> by Ken Rubin.

Discussion:

- Dr. Smith: I would like to recommend that the term complete physical dependency be removed, also.

- Dr. Brooks and Bill Allen: The appropriate recommendation would be something like “If the legislature decides not to remove all barriers in statute 765, the definition of end stage condition may not be limited to complete physical dependency.”
- Dr. Brooks: Indicated by incapacity would be still there.
- Dr. Tuch: The incapacity phrase complicates the definition of end stage condition. Because if you read the definition without the words that are in the parentheses, indicating incapacity, the definition actually makes more clinical sense. We do not need to have incapacity - it’s elsewhere defined and it confuses everyone. So, the recommendation should be made to eliminate the entire parentheses.
- Meta Calder: I still have problems with “treatment of irreversible condition is medically ineffective.” I can envision some treatments that are effective but they are not going to reverse the condition, like person with kidney diseases. There are treatments that are effective, but not reversible.
- Dr. Tuch: If the patient has an end-stage cancer condition, providing treatment, such as ventilation, is not medically ineffective in the larger context of the patient’s life.
- Mary Labyak: What we heard in testimony, given the way people die today, which tends to be from this multiplicity of diseases, isn’t this issue about people’s advance directives not being honored. Because someone can do something to keep breath going, we assume that it is medically effective. But the issue is, can this person be returned to what would be an acceptable and meaningful life? That’s why elderly with chronic illness don’t get their advance directive honored, isn’t it?
- Bill Allen: So, how would you suggest then?
- Mary Labyak: I do not know how to fix it. I just recognize the problem!
- Dr. Gomez: I think we again getting away from the person who is suffering and sick this time. I would just say that the burden of this treatment to me is greater than the benefit I am deriving from it.
- Randy Bryan: The problem is that most of the cases the patients cannot make their decisions and if so, who is going to make that decision for them?
- Bill Allen and others: That is why we have the health care surrogate.
- Ken Rubin: My recommendation would be that we need to recommend our own definition of end stage condition that makes sense to us, if we delete this, it is going to be too confusing again.
- Dr. Brooks: So, in conclusion, the motion is that if the legislature decides not to take terminal condition out, the definition of end stage condition is not limited to complete physical dependency.

**Motion withdrawn; scheduled for discussion at the next meeting.**

Kate Callahan: We’ll leave our next recommendation regarding one physician vs. two physician as it is in the interim report.

Dr. Brooks: Currently, the bill says one physician to determine the patient’s incapacity, but two physician has to determine the patient’s condition.

Kate Callahan: We think it really takes burden off especially rural area where two physicians are not always accessible. However, since DNRO has been lifted up from the Statute 765, I felt pretty unclear about the power of the proxy vs. health care surrogacy. We have to be very sensitive about this recommendation until it becomes clearer.

Bill Allen: If Dr. Brooks interpretation is correct, you are going to have to be operating it whether the health care surrogate or proxy can make decisions or not. There is a very strong argument that if the patient has not executed DNRO, neither proxy or surrogate can do it - 401 does not say a word about it. You have to import things from 765 to do that and if you are going to that, you have to deal with terminal or everything else people are trying to send.

Dr. Brooks: It is open to interpretation - we do need to develop rules and I do think it is going to become more problematic if it is challenged, in regards to what was meant because of the changes. At this moment, unless we get a strong interpretation, otherwise, we are going to proceed with rule development and DNRO form that does not require the use of the word "terminal" and requires only one physician. As for physician requirement, we have pretty clear legal ground for doing with one physician. Since there is some un-clarity here and it is my suggestion that we are going to need to ask legislature to go back next year and give us some clarification regarding 401 as well as health care surrogate and proxy. That's the Panel's responsibility. I don't think our job is to interpret the bill for the court.

Meeting adjourned @ 4pm.

**Minutes of The Panel for the Study of End-of-Life Care**  
**Friday, July 16<sup>th</sup>, 1999**  
**The Hurston Building, South Tower Orlando, FL**

**Panel Members and Alternates in Attendance:**

Susan Acker, for Pete Buigas, Agency for Health Care Administration  
Rev. Celillon Alteme, Tampa General Healthcare  
Samira Beckwith, Hope Hospice and Palliative Care  
Dr. Bob Brooks, Secretary, Florida Department of Health, alternate for Dr. Panzer  
Meta Calder, for Gema G. Hernandez, Department of Elder Affairs  
Cathy Emmett, Florida Nurses Association  
Joan Fulbright, Association of Community Hospitals and Health Systems of Florida, Inc.  
Stan Godleski, Consumer Advocate  
Mary Alice Jackson, alternate for Ken Rubin, The Florida Bar  
Mary Labyak, Hospice of Florida Suncoast  
Dr. Louis C. Murray, for Dr. Gary Winchester, Florida Board of Medicine  
LuMarie Polivka-West, Florida Health Care Association  
Marshall Seiden, Florida Association of Homes for the Aging  
Kelly Skidmore, for The Honorable Ron Klein, Florida Senate  
Dr. Alvin Smith, Oncologist, Florida Medical Association  
Dr. Susan White, Florida Hospital Association

**Advisory Board Members:**

Sonya Albury, Health Council of South Florida  
Dr. Lofty Basta, University of South Florida School of Medicine  
Dr. Ken Goodman, Forum for Bioethics and Philosophy  
Jane Hendricks, Attorney at Law  
Ray Moseley, Forum for Bioethics and Philosophy  
Dino J. Villani, Department of Health Bureau of Emergency Medical Services

**Observers:**

Dr. J. Darrell Shea  
Dr. Henry D. McIntosh  
Paul Malley  
Tanya Williams  
Randy Bryan  
Bob Jackson  
Bill Allen  
Mrs. Basta

Melissa Hardy, Executive Director.

Meeting called to order at 10:15.

Dr. Brooks. I want to be sure we get through as much of the meat of the subject while we have a quorum. I want to welcome you all back for our last meeting of the panel. I would also like to welcome a couple people who haven't been here before. Welcome Mrs. Basta accompanying Dr. Basta; we're glad to have you here. Also Paul Malley is here. Welcome. He's representing Jim Towey. Randy is here, though you were here last time. Welcome back. Everyone has been here at least once or twice before. Others I

think we know. Because of the issue that happened last time—when we lost a quorum, I do want to ask not so much for a roll call but an indication of how many voting members or alternates we have here. Remember that to be a voting alternate you or the member must have been here at more than 50 percent of the meetings. With that in mind, can I have a show of hands of members. Now if I can just count them. One, two, three, four, well, Paul is not a member. Paul, you're not a voting member. So we have 8 members. How about alternates where your member is not present? Mary Alice. Well, you guys haven't been represented 50 percent of the time. Who else is here?

LuMarie: Could Florida Health Care Association name another alternate, someone who has been here at 50% of the meetings, for another voting member? I could name someone here for the Florida Health Care Association (FHCA)

Dr. Brooks: If he or his alternate have been here more than 50% of the time, representing that seat, he would have one vote. Do you have another representative of the FHCA here?

LuMarie: No; but there are people here who have attended more than 50% of the meetings.

Bill Allen: She's looking for a proxy. She's asking if she can name a proxy for an alternate to vote.

Dr. Brooks: No, I don't think so.

Melissa Hardy: We need to have a formal appointment of the person as "the" alternate for that spot. We agreed we wouldn't allow switching alternates just to establish a vote at one meeting.

Dr. Brooks: Welcome, good to have you.

Melissa Hardy: Paul, Jackie is the Commission's formal alternate.

Paul: But we cleared this with Frank Maggio last week.

Melissa Hardy: That you were welcomed to come and participate in discussions.

Dr. Brooks: You can come and you can speak, anyone can speak, but the rules that were established a year ago were that a seat would have one vote, the member has that vote so long as they are here and that seat has been represented by one of the two people 50 percent of the time of the meetings. There has to be a representative here as a voting member. If the member is not here, their alternate can vote, but under the same guidelines. In other words if between the two of them there hasn't been 50 % participation they can't vote and that's the situation that your group is in. But you certainly can speak up and talk and participate.

Paul. Sure, but I thought that between Jim and Jackie Roberts that there had been a 50 % attendance at the meetings

Dr. Brooks. No, not at all, not even close. Ok. We have 9 members (Stan Godleski, Rev. Alteme, Marshall Seiden, Alvin Smith, Mary Labyak, Samira Beckwith, Lumarie

Polivka- West, Cathy Emmett, Joan Fulbright) and 4 alternates (Meta Calder, Mary Alice Jackson, Susan Acker, Bob Brooks) Ok, we have a quorum. A quorum has been established. And let's see. Ok that takes care of that item. I also want to add my congratulations to the new couple. May Alice and her other half, right next to her. Welcome.

Bob Jackson. We'd like to say we consider our union one of the great outcomes of this panel.

Dr. Brooks. Let's put that in the report. [applause] We've done a roll call. I want to talk a little bit about today's agenda before turning to the minutes. Given that this is our last meeting, we've got to finish up the business at hand, except for approval of the final report which we'll talk about in a moment. We want to try to get on with some of the business fairly quickly. Of course if we run out of a quorum, we might have to finish early. Hopefully we will finish with a quorum being present. What I want to do is talk a little bit about the minutes and the final report and talk about the format of the final report, and then I'd like to go through some of the recommendations from the last meeting for editorial and some noneditorial issues. Then we'll ask the workgroups if they want to change something. I understand that there are some changes that have been worked out. In thinking though the exact wording of their motions last time, they decided they needed to have that wording tweaked. And then we certainly need to get to the advance directives workgroup because it got cut off because of a lack of a quorum at the last meeting. Let's turn to the minutes. The minutes of the last meeting—I want to mention a couple things, a couple of changes that have been noted. Perhaps I misspoke, but I certainly want to change the clarification on very first paragraph which states that Dr. Brooks announces that the bill was signed by Gov. Bush on June 11. And then in that last sentence, decisions for the final report will be made on July 21.<sup>st</sup> I think that must be July 16<sup>th</sup>. With your approval that date should be switched to the date of today's meeting. What else had I noted specifically? I would ask for a motion that, if we have any grammatical changes that are needed, you would give the authority to the executive staff to change it.

Motion made by Dr. Smith, Cathy Emmett second.  
Passed with no opposition.

Dr. Brooks. The other thing that I needed to point out is that several motions are recorded in the minutes as being made by Kate who is an advisor and cannot make a motion, so we're going to have to go quickly through the minutes. Turn to page 15 for the advance directives workgroup. It has motion made by Kate and second by Ken Rubin. We'll probably talk about each of these motions again later, but I think just to be technically correct on these minutes, we're going to have to have a motion by a member or alternate, a second, and another vote on that issue so we can get that corrected in an addendum to the minutes, and then we can go on to the advance directives groups to readdress that issue if the group feels that's necessary. It doesn't have to be someone in the advance directives workgroup.

Page 15, (1<sup>st</sup> rec. by adwg) motion made by Dr. Smith, second by Stan Godleski, passed with no opposition, Dr. Brooks abstains.

Page 16, (rec. number 2) motion made by Dr. Smith, second by Stan Godleski, passed with no opposition

Page 16 # 19, motion made by Dr. Smith, second by Stan Godleski, passed with no opposition

Page 17 #20, motion was made by Dr. Smith, second by Ken Rubin, so we don't have to correct that one.

Motion to adopt the minutes, made by Dr. Smith, second by Stan Godleski.

Jane. I'm on page 20. The fax pages may be break different. We've got recommendation 3 here twice. It says addition, but it's another issue.

Dr. Brooks. Ok so there's two—the wording is clearly different. It needs to be renumbered. Ok I'm going to ask staff to go back over these minutes to clarify. It's clearly different wording so it seems it just needs to be renumbered. Probably needs to be a motion. So I'd like a motion to allow staff to renumber without changing the motion or its vote.

Motion made by Dr. Smith; Cathy Emmett second. None opposed.

Dr. Brooks. Now I'll accept a motion for adoption of the minutes. Dr. Smith. Second by Stan. Show it done.

Vote. No opposition.

Dr. Brooks. Ok as far as the final report, we do have some time constraints. We tried to get this meeting as early as we could. We have only two weeks before it's due to the legislature. And we need a week to get it printed. We need to have it to the printers Monday morning. Working back from that, we need to have comments from you guys on Friday by 3 o'clock to Dr. Hardy. We'll be working that weekend to get it all written up. Going back farther than that, what I'm going to suggest is that we will have to you guys by late Wednesday a draft version which will include today's work and revision of last month's work. Because we can't literally send you the entire final report because there are some parts of the previous report-- the interim report-- and it doesn't make sense to send it all. We will provide a table of contents and all the new material. We will have my cover letter, table of contents, changes to membership, new recommendations, a summary. We understand that's only 48 hours. I wish we could give you more time than that but the reality is that there comes a time when we have to put on the table what we have available. We will be looking for mistakes in content and in grammar. Certainly at that point we will not be able to accept anything that will require a new vote. If there is disagreement on what was passed—the chairman has tried to be careful to keep that from happening, to have motions read multiple times so everyone is clear—so hopefully that doesn't come up as an issue after today's meeting. There is no time to get the group back together; we can't even conference call because we have to notice. So when you look through that draft you'll primarily be looking at the core, to see if the intent is there, that any grammar is corrected. We will talk about the priorities of some of our recommendations today. That's the format. Melissa and I are going to work on it over this weekend and meet on Monday to try and get this product to you by Wednesday and then go from there. I think that's the best timing we can manage to get it printed and distributed to the speaker of the house, the president of the senate, and the governor. We'll talk a little bit later about some items of interest. We'll save that for later in the meeting. Votes are more important right now. We'll do that a little later.



Talking more about the format, there are two different ways to look at the final report. One is to have it be the complete document of all the year's work including the total interim report. The advantages of that are really the convenience for those who want to look at all our work. It's easier to call once and say I want to look at the work of the panel and to send out one book. I think it would be about 50 percent bigger than the interim report because it would contain all of this plus the new stuff. I don't think it would double in size because there are some things that would not have to be repeated. There is an advantage to the Pepper Institute who of course is footing much of the cost for the printing and the stockpiling of the books because they need to keep them on hand for a number of years to distribute to those who want to have access to them. When they get the request they only have to send out one book.

The other option is for us to only include highlights of this book which would be the executive summary of recommendations, the original members and panelists' information, but not put all the minutes in here for instance; the disadvantage is that if someone wants everything they have to ask for another booklet. I don't have strong feelings. A bit is up to Melissa with regard to the cost, the number of pages. I think she'll be able to tell you by Wednesday what she's going to do. Either way both will be available to the public. Either way, the new work will be up front, and the interim will go at the back. What I do know is that there will be a new letter from me as chairman, a summary of recommendations that we've come up with since the interim report. From the standpoint of those who will use this, we thought it best to mention a bit about the interim recommendations, what happened in the legislative session, something about the bill and what unfolded. Give them a historical or chronological sequence of events ending with a complete set of recommendation that have been passed since the interim report. Everything will be available to them and then can read it with some logic as to how things unfolded. I will tell you that I think we have to be careful to be true to the desires and content of what the panel has voted for. But we also need to be sensitive to how we word things. Sometimes by presenting them in a negative or confrontational way, we may do ourselves a disservice, and there are a couple areas I want to consider tweaking a little bit without changing the meaning.

And of course we'll have appendices including background information on the members and advisors, the bill itself, which will add another 16 pages but which we think will be appropriate because this will be used by people across the United States for referencing the work that's been done. Any questions or thoughts about that general scheme or time line that you want to talk about. If there's a way to do it better, we're open to doing that. We have some latitude. We want to make it as easy as possible for someone to learn what Florida's been doing. Where we're at, where we're coming from, what was accomplished this spring, what's further recommended and any reasonable reference material. And of course all our minutes at least since the January meeting. Ok? All right.

Two things we need to accomplish today, things of main concern. We do need to go over the write up of last June's paper. Sorry it took so long, but because of vacations and other things including going through the whole budget I didn't get it out to you as thoroughly or as quickly as we would have liked to. What Melissa has done is put together some information on change in membership, some of the panel activities and dates and some of the accomplishments during the legislative session. You got this? Please turn this into her at the end of the meeting today with your suggested changes so she can begin working on it this weekend. I have lots of them I already noted-- some grammatical; others are content. For example, I want to put the legislative history of the

bill in an appendix. The recommendation for the Florida legislature; these are the things we voted on last time. We're going to need to go over these today. I think the best way to do this is to allow the subgroups to start working on their areas with any new suggestions they have beginning with advance directives, and as we do that, I'm going to look at my sheet and if they don't touch on some of the motions from last time, I may make some recommendations for rewording. My hope is that we can get through the workgroups, make and vote on the motions that we can, make the changes we can, and then go on from there. OK? With that in mind I guess the advance directives workgroup is up first. Last time (page 10) we were able to vote on some things before we lost the quorum. So we need to hear from the workgroups as to whether they want to make any changes.

Jane. We have one new motion and we have some changes to 16 and 17. You want us to present our new motion? Our fifth recommendation is that

We recommend that only one physician is necessary to determine whether the medical condition or limitation referred to in an advance directive exists.

Dr. Brooks. We need a motion. Dr Smith. Rev. Alteme seconds. Any discussion on that.

Jane. We heard continually in all the forums that this was one of the hang-ups in terms of getting an advance directive implemented—the hang-up was the necessity of getting a second physician involved.

Dr. Smith: Logistically it's a problem because sometimes you have to take someone to an emergency room and on the way to the emergency room things happen.

Dr. Brooks. Any other comments. Ok. I want to make sure every motion is reread before a vote so there is no question about what we're voting on. We won't have time to revisit. One question that I have is whether the group discussed both the issue about enactment or the initial signing and their initiation.

Jane. Implementation.

Dr. Brooks: Yes implementation. So your motion relates only to the implementation?

Jane. Yes. We didn't get into capacity.

Dr. Brooks. Only the implementation of the advance directives. Let's go ahead and read it one more time.

[repeat]

Any last questions. Let's vote.

Vote. No opposition.

Jane. We have some wording changes on 16 and 17  
The first sentence will now read.

Every person in Florida has a constitutional and common law right to direct their own medical care, including the right to refuse medical treatment. This right extends to

competent and incompetent persons alike. We propose the removal of such language as “terminal condition” and “end stage condition” which may represent impediments to the implementation of a patient’s wishes. It is our recommendation that the Florida legislature remove from chapter 765 all language which stands in the way of fulfilling patients’ wishes.

Dr. Smith moves. Mary Alice seconds.

Dr. Brooks. Any further discussion. It is similar to the motion that was brought up last time. I would say that editorially it is clearer.

Jane repeated the reading of the proposed recommendation.

Dr. Smith. We’re assuming that this person had capacity at some time.

Dr. Brooks. Yes because we had that sentence put in the statute this year that this whole statute 765 does not pertain to anyone who has never had capacity. This statement clearly would be based on that building block.

Bill Allen. Sometimes by using the term wishes there, we undermine the idea that this is a person’s right. And since you began talking about every person’s right, would it strengthen the rhetoric to say “implementation of their rights.” Not their wishes. It’s a right, not “I wish somebody would allow me. “ I think it would strengthen it. We’ve gotten off on the wrong track. We’re not asking for wishes to be honored, we’re asking for rights to be respected.

Jane. Ok so the last phrase would be “fulfilling patients’ rights.”

Bill Allen. The right to direct their own medical treatment.

Dr. Basta. I would like to call it choices. Rather than rights because it’s under the umbrella of rights –that’s enormous, but these are choices made under specific circumstances, so the patient’s unique choices or expressed choices would pertain. The language becomes precise to the circumstance.

Bill Allen. I think choices is much stronger than wishes.  
Not quite as strong as rights.

Jane. We’ve got wishes in here at the end of two sentences.

Samira. I’m concerned about using choices. They have the right to choose certain things.

Dr. Basta. Yes. I have the right to choose and I choose to refuse treatment, and that is my expressed choice. Rights are a general term but here is a specific issue. My choice.

Samira. My concern is that many people tend to bundle this issue with other right to life issues and using the term choices may have people thinking about this in a different light than they should be.

Dr. Smith. I think the Supreme Court ruled that this is a right. I would think we should use the term rights. Having choices is an expression of your rights.

Cathy. I would like to echo what he just said. We started with rights and I would like to see us keep this language of rights.

Dr. Basta. Sorry. It's a right to choose. That's the right. Or to choose to forego. It's a choice within the umbrella of rights. A right to choose.

Stan Godleski. That's sort of explanatory. A lot of words can make it very confusing. People need to be able to read that law and know what it means for them.

Dr. Brooks. Does someone want to make a motion to amend the motion?

Stan. I'd like to make a motion to go with choices.—the right to choose.

Dr. Brooks. Can you fit that into the language so we all know what we're saying.

Jane. Ok, so you want choices in here once instead twice?

Stan. I'd prefer to have it twice.

Dr. Brooks. Ok Stan has made a motion to amend your motion .

Jane. And in the original I used the word wishes twice, so now we're using the word choices.

Every person in Florida has a constitutional and common law right to direct their own medical care, including the right to refuse medical treatment. This right extends to competent and incompetent persons alike. We propose the removal of such language as "terminal condition" and "end stage condition" which may represent impediments to the implementation of a patient's wishes. It is our recommendation that the Florida legislature remove from chapter 765 all language which stands in the way of fulfilling patients' choices.

Dr. Brooks. I'll take that as a proposed amendment to the motion. Any discussion on that.

Ken. I'm not sure choices clears up what we want in wishes. They're kind of vague concepts. And whether they are under the umbrella of rights or not, the point of this paragraph is an important recommendation in the history of this issue. The point is to make it strong. Exercising a right is a broader, stronger way of saying it.

Dr. Smith. The term rights should be here. I don't see any sense in obfuscating what we're trying to say. We're expressing a right. The choice is a right.

Dr. Brooks. Let me try this: if we were to take a different amendment, that had choice in the first position and right in that last statement.

Dr. Smith. The concept is that the you should have the right to express that choice. We're arguing for recognition of the right.

Stan. There are so many interpretations of what the rights are. That's why I like the term choice, which means that a person has the ability to pick something . You want a certainty treatment, it's your choice. You don't want it; it's your choice. So the term choice is one that expresses to a person his rights. I like the word choice.

Dr. Basta. To my thinking, advance care planning is a set of choices that a patient has the right to make. And that's the expression of certain choices and we cannot deviate from these. I like that the first describes choices and the last sentence ends with rights. It underscores everything that has been said here.

Dr. Brooks. So you're speaking against the current proposed amendment. Ok, well Stan, you have two choices (general laughter): What are your wishes? If you feel comfortable we can vote on choices and choices. No pressure from the chairman. Or you can withdraw your motion and I'll accept a motion that we take a different tack.

Stan. I'll withdraw my earlier motion to amend. I like that combination, too. Choices and rights. Can I offer that as a motion to amend?  
That we replace the first wishes with choices and the second wishes with rights.

Mary Alice seconds

Jane:

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. This right extends to competent and incompetent persons alike. We propose the removal of such language as terminal condition and end stage condition which may represent impediments to the implementation of a patients' choices. It is our recommendation that the Florida Legislature remove from chapter 765 all language which stands in the way of fulfilling patients' rights.

Dr. Smith. As long as we get rid of those two conditions, I'm happy.

Melissa Hardy. By choices do you mean directives. Would it clarify to call them directives?

Bill Allen. Most people don't really understand the term directives. Perhaps directions?

Samira. This is a recommendation to the legislature, not the same as a piece for public education. We want to be sure we're clear to the legislature that people have these rights.

Bob Jackson. In dealing with the legislature, I think that the choice followed by rights is best. One of the problems in the last session is that we had to explain to both the staff and the legislators that this recommendation was from a ruling which was all about a privacy right that was grounded in people making their own decisions and their own choices. I think the last draft works pretty well. It's one I'm comfortable taking to the legislators.

Paul. While we have discussion open on this topic, I'd like to note that as a representative of Jim Towey and speaking for him that he would oppose the language that calls for the removal of such language as terminal and end stage condition. And I say that just to have it noted in the report-- that he would stand in opposition to that and vote against a report that included that. And that may be an issue I need to speak with you about before the voting occurs, because I think there is a discrepancy in perhaps the meeting attendance and with the number of meetings attended either by Jim Towey or Jackie Roberts so I would just like to have that noted, that that is where we stand and where our vote would lie. And, take up whatever needs to be taken up before voting would occur.

Dr. Brooks. As chairman let me mention that as I stated before that of course we respect your comments and Jim Towey's opinion, but the issue of voting is not only due to the 50 percent vote, its due to the fact that we established a rule that alternates be identified and only alternates as identified are able to have a vote when the member is not there. Always in any democratic form, we use Robert's rules and a vote of 2/3 can change the rule, and if there is a decision by the group to change the rules, as chairman I would be willing to do that, even at the last minute. But you would need a member or a recognized alternate to make that motion with a second and to garner a 2/3 vote. But I think there is another issue, similar, that affected another person who's sort of in the same situation and wanted to designate a new person to vote, and I said no. In fairness, that is my understanding of the rules for this group. We have had a discussion and established rules for this group and I want to stick by them.

Dr. Smith. I don't want to play hardball, but I want to know is this Mr. Towey's decision or is it the Commission on Aging with Dignity? I'm a member of the Commission on Aging with Dignity and I don't believe a vote has ever been taken on this issue. This is a personal belief of Mr. Towey. And he is to represent an organization, not Mr. Towey. I represent the Florida Medical Association and we're unalterably opposed to not taking that language out. We think that that language is going to hinder the expression of the individual's rights or his choices. But there is no question that it hampers the right to life liberty and the pursuit of happiness. And I would like to ask Mr. Towey this—I'm a member of this commission and I've never been asked to vote. It's never been brought up. I'd like to have the Commission that he represents tell me what they feel, not necessarily just what Mr. Towey thinks.

Paul. I would say that I'm here representing Mr. Towey.

Dr. Smith. I don't want to make this contentious. I'm just saying I represent the 17000 doctors of the state of Florida in this association, and we strongly feel that this should come out. That this does nothing but hinder the expression of a patient's rights.

Dr. Brooks. I'm going to ask Paul, it's not just an issue of semantics, you are speaking for him?

Paul. Yeah.

Dr. Brooks. But the chair, the seat on the panel is for someone to represent the Commission. So that's I think the issue Dr. Smith is particularly concerned about.

Dr. Smith. My organization has voted on this. Voted to express this opinion.

Dr. Brooks. But in answer to your initial question, absolutely, the minutes will reflect that you were here, and you know we have a very open forum, a public forum and we certainly want to have in the minutes---which will be in the final report—that he had this concern.

Paul. And also we did speak with Frank Maggio a few times this past week and had sent written correspondence about a month ago when this meeting was announced. Jim had sent the request in that I could be alternate and have voting privileges and from everything we heard back from Frank Maggio, this request had been granted. And correspondence this past week between Jackie Roberts and Frank Maggio—that had been accepted to my knowledge.

Melissa Hardy. This is the first I've heard about a request for voting rights, so I don't know how to respond. I saw no correspondence. I'll have to check with Frank to find out what he said. I didn't authorize anything like that.

Dr. Brooks. If he said that you could come in and vote, I don't know if he did, but if he did, that would be his error; as chairman I can say that he did not do so with my permission or with that of the Executive Director. That may have been a staff technical error that well, it is possible, but my memory is, members, please correct me if my memory fails me. . .

Susan Acker. As an alternate, we can speak to the issue. I represent the Agency for Health Care Administration and in the course of the evolution of our current leadership, we have on occasion been unable to send either our official delegate or our official alternate, and I'm sure other members or organizations have been in the same situation. It is my understanding that this protocol was in fact normal, and when we did inquire about sending our most competent other spokesperson, we were told that, whereas their point of view would be entered into the minutes and the agency's perspective could be demonstrated on the issue and their expertise would be recorded, that in fact we would be able to have our position recorded but no vote counted. So these procedures have been in effect and followed.

Dr. Brooks. We have a motion on the floor which Jane has read. Are there any new points of discussion? If not, let's take a vote.

None opposed; the chairman abstains.

Jane. Just a grammatical thing—it should be his/her rather than “their”

Dr. Brooks. We voted on a motion. Well actually we voted on the amendment.

Let's vote on the motion.

None opposed: the chairman abstains.

Dr. Brooks. We need to change their to his/her.

Jane. Number 17

The legislature (as well as private sources) should fund efforts by state agencies, professional societies, universities, community colleges, and civic organizations to

educate consumers, the general public, and health care providers about patients' advanced care planning. This education should include how to implement the patient's unique wishes with sensitivity to the patients cultural heritage.

Motion by Samira. Second by Dr. Smith.

Dr. Brooks.. I want to make clear that by adopting this last motion, it serves as a substitute for the previous one. The same applies here. Any discussion?

Dr. Smith: what is actually being required here?

Jane. There's no mandate.

Dr. Brooks: Do we want to bring in the concept of encourage and provide. There are times when the legislature supplies some of the support. This wording may imply to some that we're asking the legislature to be the only source rather than play a lead role. I think we do want them to provide funding, I think everyone agrees with that, but there are times when they come up with matching programs. Should we broader from they "will fund" to they will "encourage" funding as well.

Bill Allen: encourage and provide?

Dr. Brooks. We'll need someone to propose an amendment. Mary Alice makes the motion to amend; Susan seconds. Why don't you read that again so we can hear how it sounds?

Jane.

The legislature (as well as private sources) should encourage and fund efforts by state agencies, professional societies, universities, community colleges, and civic organizations to educate consumers, the general public, and health care providers about patients' advanced care planning. This education should include how to implement the patient's unique wishes with sensitivity to the patients cultural heritage.

Dr. Brooks. Any comments on proposed amendment?

Vote: none opposed

Dr. Brooks. Lets return to the original motion.

Vote: none opposed.

Jane. We didn't really have any changes to 18. The second sentence should start "it" rather than "they."

Dr. Basta: I'd like to suggest some word changes

Dr. Brooks. First, I need a motion—Samira? OK. Dr. Smith second.

Dr. Basta: I would propose some wordsmithing. Change DNRO to DNAR—this is the general lingo now. Do not attempt resuscitation, since it doesn't always work.



The legislature should create a standardized and portable DNAR for to be used in all patient settings. Also, they should enact procedures necessary to facilitate the effective use of this form.

That would be my wordsmithing.

Bill Allen: I like the replacement of DNRO with DNAR, but the language that most people use hasn't changed enough yet. I think this change would be confusing rather than clarifying. You're way ahead of the curve on this. To change it here would be more confusing than helpful.

Dr. Brooks. If someone wanted to move that the committee encourage the legislature and everyone else to move in that direction, that would be appropriate. Do we want them to move in this directions—as a goal—that would be desirable. Recall that we use DNRO in all other places.

Dr. Smith. Most don't understand what DNRO means; to throw DNAR at them would be confusing.

Bob Jackson: I suggest that you write out "do not resuscitate."

Dr. Brooks. Yes, I had done that editorially. As we move forward, I will request a motion that allows staff and I to make these kinds of editorial changes. Any other comments on the motion on the floor?

Ok, all in favor?

Vote: none opposed.

Next?

Jane, I don't think we have any more suggested changes.

Meta. Just a comment, the way the last one is worded "since terminal was replaced in the statute", it was never really removed, so I think we should simply say, "since terminal was not removed."

Bill Allen. I'm a little confused as to the purpose of 18. Since they already gave the Department of Health the authority to do this, why are we recommending this?

Jane. You mean it was accomplished in the legislation

Bill. Yeah, I don't understand what we're doing.

Dr. Brooks. Hospital reps correct me if I'm wrong, the issue is where we have portability of the form. The new form will follow people into the emergency room, but that's as far as it goes.

Bill. If that's so then let's direct the legislature to this point. One issue also is that this says the legislature should create, rather than the legislature should delegate the authority, which is what they did.

Randy. The statute says hospital emergency services may withhold or withdraw.

Dr. Brooks. That was my memory. That we did discuss the implications of taking it into the hospital. How does this dovetail with the new directive that you may not require someone to redo their advance directives.

Jane. We're no longer calling a DNRO an advance directive.

Bill. A surrogate—if you really have divided that—then the surrogate really doesn't have the power to institute a DNRO.

Randy. I understand the point, but I disagree with the point.

Dr. Smith. The bill makes it difficult to write a DNRO. We can't do it unless a patient has a terminal or end stage condition. This has to be cleared up. We need to be able to operate efficiently and effectively, and this change is one that no one understands. As it stands, the only choice is to attempt resuscitation since he's covered in the case of liability.

Tanya. The early draft spoke to emergency rooms and we brought up the point that in 395 they don't talk about emergency rooms, they talk about emergency services and that includes the whole hospital, it is not limited to emergency rooms. So if there's confusion about this section, we need some advice from the agency hospital group, because this is a term of art in 395 about emergency services—services anywhere in the hospital.

Susan. To support what Tanya's saying, we definitely heard from the hospitals that they did not believe that this language would carry outside the emergency room, there are still areas where hospital representatives thought other parts of the hospital were sheltered from this. So there clearly are different opinions as to the implications of using the term emergency services.

Dr. Basta. I think we need some more wordsmithing. We're talking about a form. Not orders. And I would like the order to be portable in all patient care settings. Because eventually all these things will be accessed electronically.

Dr. Brooks. The word form may become obsolete.

Melissa. I thought one of the problems we discussed before was that for hospitals—when someone comes into the hospital with a form signed by a physician who was not credentialed with that particular hospital, the hospital requires that any order be written by a physician credentialed in that hospital. So the order must be rewritten.

Jane. Yes

Bill. The form may be transportable, but the order would have to be made by a different physician.

Joan. I think confusion also derives from the fact that in the hospital, this form is viewed as an expression of the patient's wishes, not as a treatment order. Inside the hospital, the order not to attempt resuscitation would have been made by a physician, the same way a prescription for a certain drug must be made by a physician even if a patient requests it.

Bill. We need to be clear what we're trying to say and how what we're suggesting here differs from what's in the statute.

LuMarie. The issue from the Alzheimer's disease physicians needs to be addressed as well.

Dr. Brooks. Interaction between 765 and 401.

LuMarie. The form and the order are different things, and the issue is who has the right to issue the order.

Dr. Brooks. Ok, let's consider where we are. Even though we just passed motion 18, we're now reconsidering whether it is necessary or whether it needs to be more specific. We need to move ahead and decide. My sense is that there may be areas that are related to DNROs and their portability that need to be worked out. The new bill addresses it somewhat. There are many issues that have yet to be worked out.

Bob Jackson. Are we wanting a state regulation to be that specific, as to what a physician ought to do in a hospital. I don't think I'm comfortable with that. The authority to write those orders is already in statute. I think we need to be careful we don't eliminate that authority.

Joan. I don't think the authority is being replaced. We're saying that the patient's wishes as expressed in this form are portable. A DNRO is based on a patient's order and is like an advance directive.

Dr. Basta. DNRO orders—there are two categories. One, the patient does not want to be resuscitated. Second, attempting resuscitation is futile—medical necessity. The issue here is portability. I am the same patient, regardless of where I am. We have to make it easy for these things to follow the patient.

Susan Acker. The enforcement issue from the Agency's perspective. I can understand when a physician practicing in an acute care setting is accountable for patient care, but I don't understand how the setting bears on a DNRO. I understand how the hospital's interrelationship of credentialed physicians occurs, but I don't understand what makes a physician's order credible to a health care intervener in a nursing home, a home health agency or anywhere else, and yet it doesn't to a health care intervener in an acute care setting. We'll be enforcing hospital wide.

Mary Labyak. Are we saying that the legislature needs to be concerned with the implementation of the standardized form. A DNRO is also an expression of the patient wishes. Shouldn't all health care providers recognize the use of this form. Part of the implementation is a regulatory issue.

Marshall Seiden. The early part of my career, we talked about DNR forms rather than DNROs. I think if we remove the 'O' it might clarify things. It turns into an advance directive that can be recognized in all settings as opposed to an order that is under different regulations.

Dr. Smith. Let's put something in that will keep them working on it.

Stan. I thought that 18 was a continuation of our concerns about advance directives. In Oregon, there is a form that follows patients. I think it's proper for it to be there as an advance directives. What's the point of an advance directive is we don't have a say in whether we will be resuscitated or not?

Dr. Brooks. Let's read the motion we already passed.

LuMarie. I have a suggestion. Add to the motion as is with. "The intent of the portable DNR form does not preclude a physician's order for no resuscitation in accordance with a patient's wishes or in cases of medical futility." Offered as a motion to replace the previous statement.

Mary Labyak. I think the wording about creating policies and procedures is cumbersome.

Mary Alice. How does this affect issues of guardianship and the kinds of decisions guardians are authorized to make?

Bill Allen. Now physicians are not required to discuss the orders with the patient. Conceptually this is not a big change from the way it is.

Dr. Basta. The area of medical futility is a very troubled waters. We have a foundation we are about the launch to explain what that is. There are not standards now. We need to develop those standards. Speaking for the motion.

Tanya. I feel strongly about Marshall's comment is that this whole thing is based in terminology that is bureaucratic. The use of the word order here is atypical of how we use order everywhere else in the medical world. We think we know what we're saying here. But I'm not sure other people will understand it. The idea is that the person's wish that resuscitation not be attempted should go with them, and the appropriate orders to implement that wish should be written, regardless of the health care setting.

Cathy. The whole thing about having the physician approach the family about obtaining permission from the family about DNR implies that there's always success with that procedure and that is just not true. In some cases, any attempt will surely fail, so why put the physician and the family through the hardship.

Susan. The agency might be contacted or concerned that a medical treatment or the withholding of services was made while the patient rights were suspended. We might view that as a suspension of the patient's rights to participate. I think the Agency will have a problem with the phrase "medical futility."

Ray Moseley. I'd be very hesitant to use terminology like medical futility since no one has defined what that is.

Dr. Basta. We need the groundwork. We need to facilitate consideration of these issues.

Dr. Brooks. In hospital, a physician who feels in his medical judgement that resuscitation attempts are futile, if I put that in the patient's form, am I not in clear standing? I don't think it's changing anything.

Ray: If you think futility is that there's only a 20 percent chance it will work, you're not on clear ground. If you mean there is no chance it will work, then you're ok.

Cathy. I was going to suggest that we table this.

Dr. Brooks. Well there's a motion on the floor. I can take a motion to limit debate, but that takes a 2/3 vote to change the rules. Tabling the motion will have the effect of killing it. Tabling kills the substitute motion.

The motion to table with 7 votes fails.

[Dr. Murray has come in.]

We're back on her motion. I can take a motion to move the question and allow the sponsor of the motion to close on the motion.

LuMarie. All I did was take your comments along with the comments of those from the Alzheimer's initiative to try to clarify who can write a DNR order and when can it be written. That was the intent of this substitute motion.

Dr. Brooks. Let's take a vote. If you want the debate to end and vote on LuMarie's motion,

Ok, we have 11 votes. The question has been called. Let's let her read it one more time so we know what we're voting on. [motion read again]

Ok this motion would replace the previous 18.

Ok, 5 in favor

8 against

1 abstention (Dr. Acker)

Marshall. **I would like to make a motion to delete the "O" in DNRO.**

Dr. Smith. I can probably second that.

Dr. Brooks. Ok do you want to hear a reading? Can we move to discussion?

Samira. Does this sacrifice consistency with other things.

Dr. Smith. All we're talking about is developing a portable advance directive, or a portable patient instruction with regard to resuscitation.

Jane. So the word "form" becomes order?

The DNR form? Ok, the DNR form.

**The legislature should create a standardized and portable do not resuscitate (DNR) form that can be used in all patient settings. They should also enact procedures necessary to facilitate the effective use of this form.**

Marshall. Given that we've wordsmithed paragraphs, sentences, and then specific words, I thought we should get down to letters.

Dr. Brooks. The chairman thanks you for helping us to focus.

Marshall. One of our physicians could take this form, regardless of where it was written or which physician signed it, and take it as advisory, and then write an order in the patient chart that reflects the patient's wishes.

Adopted without opposition.

Dr. Brooks. I see that there's some lunch set up over there. If you don't have any suggestions on 19, I have a suggestion. Right, change "replaced in the statute" to "not removed".

I'm a little concerned that we state this is "inappropriate." I think it could be misconstrued and unnecessarily negative. The terminology is unnecessary—we don't need to place blame by designating it inappropriate. Before taking a motion, Dr. Basta has some other wording, so let's let him go ahead and tell us what he has in mind.

Dr. Basta.

'The terms "mentally and physically incapacitated" were originally added to the new legislation to replace "terminal." Since "terminal" was not removed, the phrase "mentally and physically" is unnecessary and should be deleted from chapter 765.'

Dr. Brooks. Ok, do we have a motion? Samira? Dr. Smith seconds. Any more discussion? Can we vote on this?

Vote: no opposition.

Lunch Break.

Dr. Brooks. Ok, can we get back to work? We're ready to move on to the financial and regulatory working group. LuMarie?

LuMarie. We would like to consider another recommendation. One draft has been passed around. It was discussed before but not adopted. It read:

We recommend that the Legislature encourage payers of health care to purchase consultative hospice service in the areas of pastoral counseling, pain management, social work intervention and counseling and other areas of specific hospice expertise.

Bob. When I look at what was passed last time, isn't this included in the last recommendation from this working group? That the legislature create a working group, charged with a set of things. Do you want to substitute language. No?. Does it fit in this motion or is it separate. Do you want the working group to deal with it or the legislature.

LuMarie. The Legislature.

Marshall. It's a separate set of things.

Meta. How is this different from what hospice provides?

Samira. What would be helpful is for patients to have access to hospice services. A patient not eligible for hospice, they can still benefit from hospice services, it would be helpful. Now hospice is prevented from providing consultative services to these patients. There's a barrier. So we would like to encourage the legislature to remove this barrier. So hospice can provide services to patients who are not eligible for the hospice program.

Jane. Does the legislature have any voice in that.

Samira. It would allow Medicaid to establish another reimbursement category for patients not in need of hospice per se.

Mary. This is for people who don't need hospice yet, but they are grappling with issues at the end of their lives. They may be engaged in curative treatment programs, but they also want to begin dealing with end of life issues. They may also be on some kind of reimbursement that doesn't allow them to take hospice services. This would allow these patients to benefit from our services. One is an issue of that being recognized as a hospice service. For some bizarre reason, which I won't go into, regulations prevent us from providing these services even on a charitable basis. It shouldn't have to be an all or nothing thing. It shouldn't be that either you are totally in hospice or you get nothing. We would like it to be recognized that this is a legitimate service for hospice to provide. The second issue involves reimbursement. But I wouldn't want to lose the opportunity to provide the service simply because we couched it in terms of finding a way to reimburse for those services.

Tanya. Are you proposing to change a licensure law that defines what hospice is or a Medicaid law that defines what hospice services are and what therefore is reimbursable.

Mary. We would like it to be recognized that helping people with advance directives is a legitimate hospice service, but it doesn't need to be limited only to hospice patients. I'd like that to be a legitimate recognized service and not get into bizarre issues the government has raised. So just acknowledging the service in the licensure laws would help. Then we can address how to pay for it.

LuMarie. Perhaps what we can do is include in this last recommendation expanded language and the charge of the working group.

Mary. I don't think that's what we need.

Dr. Brooks. Knowing that this working group is charged with examining reimbursement methodologies, do we have a sense that we need this new motion.

Mary. But it doesn't recognize that this is a legitimate service. We've always done it. This wasn't our provision, but now that it's on the table, I would like to see hospice recognized as a legitimate provider of these services.

Dr. Smith. We need a program that allows hospice to set up a service for patients getting curative care so things will be set up for them when they need it.

Dr. Brooks. Does anyone want to speak against the motion or to amend it.

Dr. Basta. I'm a bit bewildered. I don't know what encouraging the legislature will get us. Prodding is not their forte. We are born terminal. If we are going to expand the scope of hospice we need hospice consultation at birth. No offense guys.

Bill Allen. Would this be endorsing the state to pay for pastoral services specifically.

Mary. Our efforts to counsel patients are being questioned.

Dr. Brooks. I think what we're doing here in this whole important undertaking is to give attention to the problems but to give direction, as well. As we go forward we ask them, given limited time and resources, to consider certain priorities. In that context, this comes with regard to issues of reimbursement. The language in previous motions was fairly broad. LuMarie I would like you to repeat it. When you first read it I thought it would fit into the working group charge, but if you think it needs to be separate, we need to hear it again.

Support the provision of consultative hospice service to enhance end of life care.

Marshall. Perhaps it would help to understand the reimbursement streams. They reimburse directly to a hospice; reimbursement to a hospital or a nursing home. We are proposing that there be a new kind of consideration for hospice care—as a provider of consultative services. And the fourth, which we will be discussing in a bit, is the reimbursement for physicians.

Dr. Brooks. We don't officially have a motion on the floor.

Marshall. There is another role for hospice that should be recognized and that is as provider of consultative services.

Samira, As much as we appreciate concerns about making these services reimbursable, what we would like to see is the opportunity to provide these services. Up until a few years ago, hospices could provide advice, but we are now prevented from providing advice and information and answering questions. And now we can't do that. As much as we appreciate the tie in with the money, we would like to be able to provide these services.

Bob Jackson. All of this is couched in reimbursement kinds of verbs. If there are regulatory barriers that keep hospice from providing the kinds of consultative services you want to provide, you need to word it differently. This appears to me to say you want these services included in covered services by Medicaid. Is there a law or rule or Medicaid regulation that says you can't do it? That's different than saying you can't get reimbursed for it. I'm trying to figure out what the problem is.



Susan Acker. We are talking about operation restore trust and some of those issues. If we're talking about the fact that a hospice representative is preemptively excluded from a health care facility, then I know of no regulations that apply here.

Mary. It does deal with Operation Restore Trust in that charitable community based and free services might be provided with the wrong intent.

Dr. Smith. Our home health agency would be happy to use that service if they could. But the government views it as an enticement to go into the hospice care when that time comes.

Dr. Brooks. Is that because of state concerns or because of HCFA or other federal regulations?

Samira. Some are federal.

LuMarie. How about this as a motion:

Recommend that the legislature remove regulatory barriers to the access of appropriate hospice services including consultation and early intervention programs for the enhancement of end of life care.

Motion made by LuMarie and second by Dr. Smith.

Mary Alice. Are there people who provide hospice like service who aren't hospices.

Susan Acker. Patients in other health care settings can have those needs addressed . They may not have the comprehension or access or all the resources of a hospice. But we have people who are providing pastoral and palliative care who are not hospice.

Bill Allen. Should we be saying hospice-like services?

Dr. Brooks. Any other discussion of that motion. Everyone ready to vote.

Vote. No opposition; Susan Acker abstains.

LuMarie. Recommend that insurance plans, managed care plans, Medicaid include advance care planning as a reimbursable service.

Motion made by LuMarie; second by Dr. Smith.

Dr. Basta. Who would be reimbursed for providing these service?.

Bill Allen. In our last meeting, I recall that Dr. Tuch said this is already reimbursable; it is not widely perceived, but it is.

Dr. Smith. There is a code in Medicare that can be used to denote palliative care, but it is not a reimbursable code.

Dr. Brooks. The desire is to bring renewed attention to this. I guess the question to be asked is whether including this will confuse people. Is this to further recommend or further encourage.

LuMarie. It is to encourage insurance plans and managed care plans to provide reimbursement for these services. So it is broader than what is currently in place.

Ken. Most things that you can be reimbursed for, you've had some training in how to do. Without linking this reimbursement to training, it implies that anyone has the skills required to do this well. I'm not sure what counts as appropriate training.

Rev. Alteme. There is reimbursement for pastoral care where there is training in pastoral education. A hospital can bill Medicare for the providing of pastoral care when the hospital—the center—has a program in pastoral education.

Dr. Smith. That's why you have hospitals including center in their names.

Dr. Basta. I agree with the notion that you must have training to provide the service, especially if you want to be reimbursed for it.

Dr. Brooks. LuMarie, can you read it again, and if someone wants to offer an amendment. You really don't bring up who should do it or training. If we want to do that, we're probably going to have to be much more specific, listing the specific professionals who could do it. The way it's stated now is very broad. We aren't advising the Legislature as to whether we're talking about physicians.

Dr. Basta. It's a fact. If a physician is reimbursed for it, they will do it. I would like the motion to be for physicians, and all the rest of it will follow.

Dr. Brooks. At some point, Marshall said something about a physician reimbursement motion or recommendation. Is this it?

Marshall. Yes.

Dr. Brooks. The more specific we are to the legislature, the less likely they may misunderstand what we mean. Some of what we have is quite broad; others are very specific. If someone wants this motion to be more specific, someone must amend it.

Cathy Emmett. Nurse practitioners are probably the ones who are doing more of this than physicians, so I'm not sure we want to limit it to just physicians.

LuMarie. Let's try this revision.

Recommend that insurance plans, managed care plans, and Medicaid include advance care planning as a reimbursement-coded service when provided by professionals trained in end of life and palliative care.

Rev. Alteme. For example, the center cannot call a pastor from outside to provide this kind of care. It must be someone from the program, a recognized program.

Bob. Hi Kelly. Welcome.

Mary Labyak. We don't want to limit the discussion to those who will have this discussion in the last two days of life. We want to encourage advance planning at an earlier stage.

Samira. Isn't end of life the same as palliative care.

Dr. Brooks. No. Dr. Tuch isn't here to defend the difference. There are similarities but they're not identical.

Dr. Murray. They aren't synonymous.

Dr. Brooks. Any other issues to discuss. Ok.

Vote. No opposition.

Dr. Brooks. I have a couple minor things. On page 7 of the 7/15 draft. In the first recommendation, for clarification, I would like to add in parentheses "not just HIV/AIDS" so it's clear we recognize what they did this year and how we want it expanded.

Marshall moves; Mary seconds.

Vote. None opposed.

Dr. Brooks. I'd like to have the editorial license to change the order. I think there is a more logical progression of these recommendations. It's less about the message, more about a logical progression from one recommendation to the next. I thought the one at the bottom—currently number 6—which deals with public education should go first. We've emphasized the importance of public education, and I was thinking it made sense to begin with that one. And then I thought we should go to the recommendations about the education of providers. Beginning with the second, third, fourth and fifth—we would follow in that order, and then list the one that is currently first, the one we just finished, and then to the next page. Is that ok with everyone? Is there a motion?

Dr. Smth moves; second by Susan Acker.

Mary Alice. I thought I would just make a motion to allow you to do that generally throughout the document.

Dr. Brooks. Well, I appreciate that, but I didn't want to do it myself, since someone might interpret a change in the numerical ordering as a change in priority. I don't think that's necessarily the interpretation that will be made, but I wanted to make sure everyone was ok with the order I was suggesting. So since we have a motion on the table, I'd like to go ahead and take a vote on that.

Vote. None opposed.

I had the same sort of thing in mind for the next section. I think we should switch the first and the second under pain and palliative care. I'd start with the one currently second, since it involves a definition. Then change the first one to second. Make number 3 the one about hospice on the next page. Then move to what is currently #14 and make that the fourth. Then back to the one at the bottom of page 8 beginning "Where appropriate"—make that number 5, the one above it number 6, change the current #13 to number 7 and the current number 15 to number 8. I think our theme really truly has been getting the populace and providers educated, so I'd like to consistently put those ideas at the top of the lists. Is there a motion?

Dr. Smith moved, Dr. Acker seconds.

Vote. None opposed.

Dr. Brooks. Now I guess we should see if the pain management and palliative care group wants to make any changes.

Marshall. I have to leave . . . could I have a minute?

Dr. Brooks. Sure.

Marshall. I have to leave early. I want to say that this has been a terrific experience. Speaking for myself I've learned an awful lot about this topic, coming into this thinking you know a lot and come out thinking how little you did know. I hope—and I believe it is very important for the state of Florida—I've learned that not many states have taken these kinds of steps. I want to thank everybody. I hope we do find a way to keep this going.

Dr. Brooks. Thank you Marshall. We thank you for your time and your organization's efforts.

OK. Dr. Tuch isn't here. Who will present for this group. Nothing specific? Well let's take a look at page 8 under the group's heading. I had a thought about clarification—in the second recommendation that includes the definition—I'm not sure where the quote ends.

Samira. I think there is something in the definition that says something about quality of life.

Cathy Emmett. I think all of that is the quote—to the end.

Dr. Brooks. Ok, well I guess we can check with Dr. Tuch to be sure. I just want to be sure.

Also, I just got a letter from Dr. McIntosh—was there an issue there in relation to the definition of palliative care and a difference between the definition that Project Grace is adopting—a different definition from this one. I just want to say that I think our groups have worked well together, that we complement each other, and we don't want to take an action that presents us in opposition. We don't have to use the same definitions, but let's talk about that. Dr. Basta? Dr. McIntosh. We were just very specific in our recommendation, that the legislature adopt a definition that is identical to that of the

World Health Organization, and perhaps we should recommend that they adopt a definition such as that of the World Health Organization.

Dr. McIntosh. We were using the definition provided by the Robert Wood Johnson Foundation Last Acts Project. I have it here. It says:

“Palliative care refers to the comprehensive management of physical, social, spiritual and existential needs of patients in particular those with incurable progressive illnesses. Palliative care affirms life and regards dying as a natural process that is a profoundly personal experience for the individual and family. The goal of palliative care is to achieve the best possible quality of life through relief of suffering, control of symptoms, and restoration of functional capacity while remaining sensitive to personal cultural and religious values beliefs and practices.”

Cathy Emmett. I'd like to move that we broaden the recommendation by saying such as rather than identical to.

Kelly seconds.

Mary Labyak. I think we should leave this more open ended. The world Health Organization definition was done quite some time ago. There's the definition from the Last Acts, and other definitions are being constructed that are broader and more comprehensive than the one of the World Health Organization. We should accept other broad based universally accepted definition.

Cathy Emmett. I don't have any problem with RWJ's definition, but I'm not sure I think we should leave it totally open in terms of acceptable definitions.

Dr. Basta. Would this group care to substitute?

Dr. Tuch. I wouldn't like to do anything that drastic, since Dr. Tuch isn't here to give us his reactions. I think we should open the door wider. I don't see a problem with the WHO definition.

Bill Allen. He didn't say it was the only definition, but he did prefer it.

Samira. The two definitions are not in conflict. They address many of the same issues.

Stan. We like a lot of words, it seems. But as I read this, what is in this new definition that is not included in the other definition of palliative care.

Samira. I think the RWJ definition is more expansive.

Dr. Brooks. Right. The two definitely don't conflict. I just was concerned with the term identical, so it doesn't suggest that we have a particular problem with this other definition.

Kelly. Why not use the term “similar to?” Then any definition close to that of the WHO would work?

Dr. Brooks. Is that a friendly amendment?

Cathy. Yeah. The Legislature should adopt a definition of palliative care that is similar to that of the World Health Organization . . .

Vote. None opposed.

Jane. Now we need to tinker with the first one.

Meta. Why don't we amend by ending the first sentence after "services."

**The Legislature should 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 possible quality of life for patients and their families.'**

Motion. Meta. Second. Cathy Emmett.

Vote. None opposed.

Jayne. Wait the third one. Last line. It says "palace" and we need to change it to "place."

Dr. Brooks. Ok. Well it's been brought to my attention—can we return to advance directives. Dr. Hardy has noticed—as a point of discussion—we reworked the phraseology of the last recommendation. She questions whether we should state "If terminal is not removed. . ." That tightens up on that concept.

Meta. What if terminal is removed, do we still want it in there?

Bill Allen. It was an explanation for why it was put in. It's not a justification for keeping it.

Bob Jackson. It's a problem to define what mental and physical incapacity is.

Bill Allen. Why not strike the explanation?

Dr. Brooks. You're suggesting we strike the first two lines.

Jane. Don't give them any history.

Dr. Brooks. You could just say, "The terms mentally and physically" are confusing and unnecessary and should be removed." Does someone want to make a motion on 19?

LuMarie makes motion. Susan seconds.

Bob: This motion would replace the one made earlier this morning.  
How would it read:

**“The phrase “mentally and physically” is confusing and unnecessary. We therefore recommend that the phrase “mentally and physically” be deleted from Chapter 765.”**

Vote. None opposed.

Bob. Can I have a motion that allows us to do some minor rewording and changes for grammar's sake in the report.

Motion by Smith; second by Dr. Murray.

Vote. No opposition.

Stan. We're coming to the end of our time. When we first started, I wondered how all of this would come out. There's so much knowledge here; so much mental power. Will we agree with each other? And lo and behold it's been a wonderful, wonderful experience for me to see the presence of such power. Whoever brought this committee together deserves great congratulations. And number two, I've never met a chairman, and I've been on many boards, who conducted a meeting with the aplomb, sophistication, patience and statesmanship of this gentleman. [applause]

One concluding statement because we're all here because we feel a certain feeling for other human beings and that became very visible. My mother who was an immigrant to this country said to me when I went out to my first job, "Remember, have a heart." The heart my mother alluded to is in abundance in this committee. I am reminded of a small segment of a poem by the Lebanese poet Gibran. The poem spoke about giving from the heart. ". . . Through the hands such as these God speaks, and from behind their eyes, He smiles upon the earth." I love you all.

[applause]

Dr. Brooks. That was very kind of you to say. But you know a chairman is only as good as his committee, and I look around this room and am awestruck at the many many years of experience represented around this table. Before thanking you all, I did want to give a few minutes to talk about some items of interest. We have issues related to a grant proposal, demonstration projects, and any other items people may want to share. Samira.

Samira. I just wanted to update the committee on the community state partnership proposal to RWJ that a number of us have submitted. Our grant has been accepted for a site visit, which is the next step in the process, probably some time in August. We hope it will be funded. We also hope we might be able to use the grant to continue the momentum that has been built over the next year and continue the work of the panel. I would like to warn you that you will be hearing from me asking you to be advisors to the project so that we can continue the implementation and continue to work together.

Dr. Brooks. That's nice. We wish you success. Look forward to hearing about the progress. Dino do you want to say something about the demonstration projects.

Dino. The demonstration projects were described to you in a note from Freida. We will be in the process of looking them over and evaluating them. One of the projects is from Rep Greenstein about the smart card. Concerning the DNRO, here's the Freida Travis smart card, I'll pass it along. We're having some more meetings on the standardized

form—two more. The first is in Miami on July 21<sup>st</sup> in Miami at 10 at 8000 West First S Street. The second is on the 22<sup>nd</sup> in Tallahassee to deal with the form and the card, etc.

Dr. Brooks. I want you guys to have a few moments to talk about other items of interest. I'll take a few moments now to make a few comments regarding my thanks to you. We've accomplished some great things, more than I imagined we could over a year ago, even more than uniting some in marital bliss. The relationships formed and discussions embarked upon have resulted not just in specific legislative changes, but I believe that through the public forums and the press we've generated that more people are attuned to what's going on. We've raised some new questions, new things do deal with, but we've made a real contribution. And I want us to give a huge round of applause to our Director Melissa Hardy. She's really extended herself. She's been willing to put herself out for us. As you know from the beginning she's had no budget, a few contributions from some organizations, which was very much appreciated. But she did this—and how many meetings are we up to, 16, 17 meetings, essentially all day meetings—and through their graciousness, we've been able to accomplish so much. I plan to write a letter to her bosses at FSU to thank them for all the support. I also want to mention that for those of you who are regular members and alternates, we will have some certificates signed by the Governor and by myself as a small token. My hope is that we will be able to continue to work together. We have some issues here at the Department of Health and I plan to be in contact with you guys to use the brain trust and the personal trust we've developed for the betterment of the state. And that's all I have to say from my standpoint. Thank you for the honor to serve. And I look forward to getting your comments this week so we can get our product out this week.

Dr. Smith. I would like to be able to extend to the newlyweds a token of our good wishes. The research you know is unequivocal that married people live longer.

Mary Alice Jackson. On behalf of the bar, it has been unusual to be asked for our input. I'm sorry that Ken is not here because he did such a marvelous job with this group, we'd like to express our appreciation. Jane has served on our own accord. To be recognized and included in this initiative as private practitioners, dealing with our clients, has been so very valuable. We hope you will call on us. We appreciate being a part of this.

Dr. Brooks. Thank you very much. We all understand how very important the input of our elder law attorneys has been to this whole process, helping us understand what is legal and what is not.

Dr. Basta. Likewise, I would like to thank all of you for giving us the opportunity to participate. You listened to us and we learned a whole lot from you. Project Grace has been active for a year now. We came up with task force recommendations that would complement and address the same things that you have laid the groundwork for. We are launching a nonprofit foundation to carry the banner for continued education, public education, and other guidelines. We have a very ambitious agenda. Dr. Henry McIntosh has served with us and many here are on our Board.

Dr. McIntosh. I am so proud of you people and what you have done. Because all around the country, I don't know of any state where the people have made such an impact. Your efforts make Florida among the leaders in this very important area.



LuMarie. In addition to your fine leadership, Dr. Brooks, I would like to support recognition of Melissa Hardy and how valuable she's been to all of us. She's always been there when we needed her and been very responsive throughout the legislative session offering testimony to many of the committees. I also want to recognize the legislative staff, Kelly and the wonderful job she did, also Senator Klein and Rep. Argenziano, and Melanie Meyer for all the hard work they did on this legislation.

Dr. Brooks. Yes, absolutely. On behalf of this panel and for myself, our thanks to the Senator for his work and interest in these issues and to the staff who worked the legislation.

Kelly. We are the catalyst for what's been going on in other places around the country.

Dr. Brooks. I'd be glad to accept a motion to adjourn.

Dr. Smith. So moved.

Bob. Without any objection, we are adjourned.