



Workgroup Report

Submitted:
December 31st, 2000



*Administered by:
Florida Department of Elder Affairs*

*Gema G. Hernandez, D.P.A.,
Secretary*

Recommendations



JEB BUSH
GOVERNOR

GEMA G. HERNÁNDEZ, D. P. A.
SECRETARY

December 31, 2000

The Honorable Jeb Bush, Governor
The Honorable John McKay, Senate President
The Honorable, Tom Feeney, House Speaker

The 2000 Florida Legislature created, in CS/CS/1890, the End-of-Life Care Workgroup. This 18-member workgroup was directed to: 1) Examine reimbursement methodologies for end-of-life care; 2) Identify end-of-life care standards that will enable all health providers along the health-care continuum to participate in an excellent system of delivering end-of-life care; and 3) Develop recommendations for incentives for appropriate end-of-life care. I have been honored to facilitate this workgroup and assist its work on this extremely important area of public policy.

From August to December, the workgroup held a series of six meetings to develop recommendations regarding reimbursement methodologies, end-of-life care standards, and incentives for appropriate end-of-life care. Summaries of the meetings, work, and recommendations are contained within this report. For the most part, the workgroup held a high degree of consensus regarding each of the recommendations. A few of the workgroup's recommendations may need further study. I would be glad to talk with you regarding any of the recommendations. I am strongly committed to the workgroup's recommendations which provide for culturally and linguistically appropriate training and education on end-of-life care.

I would like to acknowledge the tireless work of those who served as workgroup members and advisors. Without the members' commitment the workgroup would not have been able to accomplish their task in the short time allotted. The workgroup hopes that through continued public interest and legislative debates that end-of-life care will remain a high legislative priority.

Committed to working together for older Floridians, I am . . .

Sincerely,

Gema G. Hernández, D.P.A.
Secretary, Florida Department of Elder Affairs

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EXECUTIVE SUMMARY

The End-of-Life Care Workgroup, Chapter 2000-295, Laws of Florida, was signed into law on June 15, 2000. This 18-member workgroup was directed to submit a report to the Governor, Speaker of the House, and President of the Senate by December 31st, 2000, that would:

- 1) Examine reimbursement methodologies for end-of-life care;
- 2) Identify end-of-life care standards that will enable all health providers along the health care continuum to participate in an excellent system of delivering end-of-life care; and
- 3) Develop recommendations for incentives for appropriate end-of-life care.

The Department of Elder Affairs (DOEA) facilitated and provided staff support to the workgroup. There was no appropriation for the workgroup and all members served without compensation. The workgroup is composed of representatives from the Florida Senate, Florida House of Representatives, state agencies, professional associations, and advocates including:

Florida Assisted Living Association (FALA),
Florida Association of Health Maintenance Organization (FAHMO)
Florida Association of Homes for the Aging (FAHA)
Florida Association of Insurance and Financial Advisors (FAIFA)
Florida Department of the Agency for Health Care Administration (AHCA)
Florida Department of Elder Affairs (DOEA)
Florida Department of Health (DOH)
Florida Health Care Association (FHCA)
Florida House of Representatives
Florida Hospices and Palliative Care, Inc. (FHPC)
Florida Hospital Association (FHA)
Florida Life Care Residents Association (FLiCRA)
Florida Medical Association (FMA)
Florida Nurses Association (FNA)
Florida Osteopathic Medical Association (FOMA)
Florida Pharmacy Association (FPA)
Florida Senate
Florida State Oriental Medical Association (FSOMA)

Between August and December, the workgroup held a series of six public meetings designed to develop recommendations regarding reimbursement methodologies, standards, and incentives for appropriate end-of-life care. DOEA published a public notice of each End-of-Life Care Workgroup meeting in the Florida Administrative Weekly (FAW).

Summary Recommendations

The workgroup was directed to report their recommendations to the Governor and Legislature by December 31st. Workgroup members were encouraged to raise other relevant issues for discussion. Background information and the rationale for each recommendation are provided in the body of the report.

After much deliberation and based on nationally accepted and consensus based standards, the End-of-Life Care Workgroup developed the following recommendations:

1. To provide the public-at-large education that is culturally relevant and linguistically appropriate on end-of-life care, with specific initiatives for rural and other under served populations as provided in section 765.102 (5), Florida Statutes.
2. To initiate a demonstration project to identify the methods and costs of high quality end-of-life care in all types of Florida health care facilities including complementary or alternative medicine/therapies.
3. To amend section 456.033, Florida Statutes, to include Certified Nursing Assistants.
4. To add best interest to Chapter 765, Florida Statutes as follows:
 Substituted judgment must be the preferred standard of decision-making used by health surrogates, durable powers of attorney for health care, and proxy decision-makers, but when there is no indication what the principal would have chosen, proposed or currently in effect, treatments may be withheld or withdrawn by the surrogate, durable powers of attorney for health care, or proxy's decision under a best interest standard.
5. To delete from Chapter 765, Florida Statutes, the threshold alternative criteria required to be certified in order to withhold or withdraw life-sustaining treatment.
 - If the above criteria is not omitted, "end stage condition" definition should be changed to read as follows:
 Section 765.101(4), Florida Statutes, end stage condition means a condition that is caused by injury, disease, or illness which has resulted in progressively severe and permanent deterioration, and for which the patient, resident, or authorized representative would deem life-prolonging treatment to be more of a burden than a benefit.
6. To add the following definition of palliative care, which was adopted by Palliative Care Task Force of Last Acts Organization in December 1997, to Chapter 765, Florida Statutes:
 "Palliative care refers to the comprehensive management of the physical, psychological, social, spiritual, and existential needs of patients. It is especially suited to the care of people with incurable, progressive illness."

Source: Task Force on Palliative Care. "Precepts of Palliative Care." Last Acts. (December 1997).

7. To increase access to end-of-life and palliative care, add the following proposed language to Chapter 765, Florida Statutes:

State health and long term care organizations and individual health and long term care entities should evaluate:

- (a) The adequacy of their end-of-life and palliative care services including cultural appropriateness;
- (b) The relevant reimbursement policies which ensure availability of end-of-life and palliative care; and
- (c) Applicable administrative and regulatory barriers to end-of-life and palliative care.

8. To add the following standards to Chapter 765, Florida Statutes.

Palliative care must include an:

- 1) Opportunity to discuss and plan for end of life care.
- 2) Assurance that physical and mental suffering will be carefully attended to.
- 3) Assurance that preferences for withholding and withdrawing life-sustaining interventions will be honored.
- 4) Assurance that the personal goals of the dying person will be addressed.
- 5) Assurance that the dignity of the dying person will be a priority.
- 6) Assurance that health care providers will not abandon the dying person.
- 7) Assurance that the burden to family and others will be addressed.
- 8) Assurance that advance directives for care will be respected regardless of the location of care.
- 9) Assurance that organizational mechanisms are in place to evaluate the availability and quality of end-of-life and palliative care services.
- 10) Assurance that necessary health care services will be provided.
- 11) Assurance that the above will be done in culturally appropriate manner.

9. To initiate Assurance that a demonstration project that would:

- (a) Identify current research relevant to end-of-life and palliative care in Florida communities attention to be given to research dealing with culturally distinct populations;
- (b) Enhance quality and access to end-of-life and palliative care services especially in rural, uninsured, and minority communities;
- (c) Develop collaborative research and demonstration partnerships; and
- (d) Disseminate the results of current research using culturally appropriate mechanisms.

10. To promote public and professional education in end-of-life care standards, add to Chapter 765, Florida Statutes.

A. Public

- 1) The appropriate state agency will identify and coordinate existing training programs and materials on palliative care that would be available in all communities and collaborate with programs such as Robert Wood Johnson Foundation (RWJ) Partnership for End-of-Life Care Grant to promote community awareness and skills of surrogate and proxy decision makers. Determine the need for and establish new programs on training of surrogate and proxy decision makers that includes cultural values, beliefs and practices to ensure ongoing programs meet community needs. The program components should include:
 - a) Consumer choices and responsibilities,
 - b) Culturally appropriateness and linguistically diversified,
 - c) Expectation for access to effective pain management and palliative care in all health care settings,
 - d) Advance Directives and Surrogate/Proxy decision makers, and
 - e) Targeting elders, their children, and caregivers in a public relations effort to improve their decision-making.

B. Professional

- 1) Encourage educational institutions to establish or enhance curricula to rapidly improve training in palliative care for physicians, nurses, counselors, social workers, pharmacists, or any other end-of-life care provider.
- 2) Encourage the use of established end-of-life care professional curricula in Continuing Medical Education (CME) and Continuing Education Unit (CEU).
- 3) Encourage the development of a palliative medicine fellowship programs in the four medical schools in the state.
- 4) Encourage the inclusion of culturally appropriate materials.

Other Issues Identified by the Workgroup

- Case managers from Elder Services reported that law enforcement officers and fire fighters have not been honoring Do No Resuscitate Orders (DNROs) because they may not have protection from liability.
- Military physicians are excluded from writing DNROs because they are not licensed by the State of Florida.
- DNROs use the term “may” instead of the word “must”. The use of the term “may” in the DNROs was raised this serious question. The general legislative intent expressed in Chapter 765, Florida Statutes, is extremely clear and strong on the point of assuring people that their decisions to refuse treatment will be followed. The use of the term “may” creates confusion and provides reluctant facilities or providers a plausible argument that they are not legally obligated to follow a patient’s DNRO.

INTRODUCTION

Death is a part of the human experience and everyone expects to receive humane care at the end of their life. The reality is that all too often those expectations are unattainable. More Americans die in institutions such as hospitals and nursing homes rather than in their homes causing many individuals to find themselves isolated in the final stage of life. The dying process today tends to be more prolonged, in part because medical treatment and advances in technology, procedures, diagnostics, and pharmaceuticals, can better manage common and complex medical conditions.

Quality care at the end of life has become an increasing concern for Floridians with approximately 160,00 individuals dying in Florida each year. Modern advances in medical science and technology coupled with Florida’s aging population, creates an imperative for public policy-makers to continue their efforts to address barriers to quality end-of-life care. This report describes the activities and recommendations of the End-of-Life Care Workgroup.

Mission

In August of 1999, the Panel for the Study of End-of-Life Care (also known as “the Panel”) recommended the creation of a workgroup to examine reimbursement methodologies, identify end-of-life care standards, and develop incentives for appropriate end-of-life care. In response to the Panel’s recommendation, the Florida’s 2000 Legislature created the End-of-Life Care Workgroup, Chapter 2000-295, Laws of Florida, within the Department of Elder Affairs. Table 1 outlines the workgroups directives and reporting requirements.

TABLE 1 End-of-Life Care Workgroup (Chapter 2000-295, Laws of Florida)	
Authorization:	Section 16 of Chapter 2000-295, Laws of Florida creates within the Department of Elder Affairs the End-of-Life Care Workgroup. The workgroup shall exist for 1 year and shall meet as often as necessary to carry out its duties and responsibilities. DOEA shall provide staff support within existing resources.
Directives:	The End-of-Life Care Workgroup shall: <ol style="list-style-type: none"> 1. Examine reimbursement methodologies for end-of-life care; 2. Identify end-of-life care standards that will enable all health providers along the health-care continuum to participate in an excellent system of delivering end-of-life care; and 3. Develop recommendations for incentives for appropriate end-of-life care.
Reporting:	The End-of-Life Care Workgroup shall submit a report to the Governor, President of the Senate, and the Speaker of the House by December 31, 2000.

Membership

The 18-member workgroup is composed of representatives from the Florida Senate, Florida House of Representatives, state agencies, professional associations, and advocates. Between August and December, the workgroup held a series of six meetings. All workgroup members served without compensation. The Department of Elder Affairs facilitated the workgroup, and provided staff support within existing resources. Public input was received at each of the workgroup meetings. Mr. Bill Allen, J.D., of the Florida Bioethics Network served as an advisor to the workgroup. A list of the workgroup member organizations are listed below in Table 2.

TABLE 2 End-of-Life Care Workgroup Membership	
Agency for Health Care Administration	Susan Acker, R.N., Ph.D.
Florida Assisted Living Association	Henry Pearson
Florida Association of Health Maintenance Organization	Sharon Zill, Ph.D.
Florida Association of Homes for the Aging	Marshall Seiden
Florida Association of Insurance and Financial Advisors	Julia Herndon
Florida Department of Elder Affairs	Gema G. Hernandez, D.P.A., and Marshall Kelley
Florida Department of Health	Freida B. Travis
Florida Health Care Associations	Howard Tuch, M.D.
Florida House of Representatives	Representative Heather Fiorentino
Florida Hospital Association	Susan White, Ph.D.
Florida Hospices and Palliative Care, Inc.	Samira Beckwith, MSW
Florida Life Care Residents Association	Peg Terbeek, Member
Florida Medical Association	Alvin E. Smith, M.D.
Florida Nurses Association	Cathy Emmett, ARNP
Florida Osteopathic Medical Association	JoAnne Bujnoski, D.O.
Florida Pharmacy Association	James Powers
Florida Senate	Senator Ron Klein
Florida State Oriental Medical Association	Richard Freiberg, D.O.M., D.Ac, Dipl. Ac.

Workgroup Recommendations

Reimbursement Methodologies

RECOMMENDATION #1 - PUBLIC EDUCATION ON END-OF-LIFE CARE

Since World War II, this country has focused socially and medically on advances in curative treatments, which keep people living longer and healthier and battling heretofore deadly diseases with vaccines, antibiotics and a host of internal and external ways to defy death. This remains ingrained in our culture, and the naturalness of death and the ways to help people deal with chronic and terminal infirmities has been ignored to the point that we have become a death denying population. Most people do not prepare for the reality of death.

The workgroup determined there is a need for end-of-life care education for individuals in the private, public, and professional sectors. Presently, there is a lack of reimbursement and incentives for providing this type of education to all populations, thereby bringing better care to the dying and treating death as a normal human experience.

The workgroup's specific recommendation #1 is:

- To provide the public-at-large education that is culturally relevant and linguistically appropriate on end-of-life care, with specific initiatives for rural and other under served populations as provided in section 765.102 (5), Florida Statutes.

RECOMMENDATION #2 – CREATING CHOICES AT THE END-OF-LIFE –WHAT, WHEN, WHERE AND HOW

There have been studies over the last several years concerning patients who are diagnosed with terminal conditions and the type of treatments they have received in medical institutions. Many individuals facing the end of their lives have not received the type of treatments that reflected their own wishes to avoid unwanted life-prolonging therapies or pain and symptom relief to experience quality of life for whatever amount of time is theirs to enjoy.

There are many settings in which individuals receive end-of-life care: private home with no outside care; private home with hospice or home health care; long term care facility; acute care hospitals; assisted living facility; free-standing hospice residence; or inpatient facility. People deserve to have choices of where and how they receive care at the end of life. There should be financial and educational incentives for developing a credible continuum of care for all people at the end of life.

There can be a workable continuum developed to enhance care at the end of life. Health care facilities/programs could receive credit for promoting such a continuum of care. Long-term care settings should work cooperatively with Hospices and end-of-life care specialist to improve end-of-life care. This relationship could be considered as a component for Gold Seal providers and all providers in the long term care arena.

Continuing education programs such as end-of-life care continuing medical education (CME) and continuing education unit (CEU) could be provided as incentives. Adult day care programs could work cooperatively with Hospice programs, along with acute care hospitals developing similar working relationships with Hospices to develop and maintain end-of-life and palliative care programs.

The workgroup's specific recommendation #2 is:

- To initiate a demonstration project to identify the methods and costs of high quality end-of-life care in all types of Florida health care facilities including complementary or alternative medicine/therapies.

RECOMMENDATION #3 - CERTIFIED NURSING ASSISTANT CONTINUING EDUCATION REQUIREMENT

Last year a Legislative provision was passed into law which allowed all health care professionals the right to substitute palliative care education for the currently required HIV/AIDS continuing education requirement when appropriate. Certified nursing assistants (CNAs) were unintentionally left out of last years statutory revisions. The workgroup recommendation is to include CNAs, thereby remedy this technical oversight.

The workgroup's specific recommendation #3 is:

- To amend section 456.033, Florida Statutes, to include Certified Nursing Assistants.

End-of-Life Care Standards

Standards for end-of-life care encompass a variety of different disciplines in the health care arena including, but not limited to: oncology; palliative care; primary care; nursing; counseling; clergy; physical therapy; speech therapy; occupational therapy. At this time comprehensive standards for end-of-life care are still in development. Several health care research foundations such the Robert Wood Johnson Foundation (RWJ) and the Institutes of Medicine have funded numerous projects to develop standards for end-of-life care. Various disciplines have developed end-of-life care standards, examples of these are:

- American Association of Colleges of Nursing. "Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care." (1999).
- Hallenbeck, J. "Best Practices in the Care of the Dying." *Annals of Long-Term Care*. Vol. 8 No. 7 (July 2000) 39-44.
- Cassel, C.K., Foley, K.M. "Principles for Care of Patients at the End of Life: An Emerging Consensus Among the Specialties of Medicine." (December 1999).
- MacLean, D.S. "AMDA Model Care Facility." *American Medical Directors Association Web Page*. <<http://www.amda.com>>.
- Schall, L.J., Nolan, M.C., Kabcenell A. "Quality Improvements in End-of-Life Care." *The Joint Commission Journal on Quality Improvement*. Vol. 26 No. 5. (2000). 254-67.
- Task Force on Palliative Care. "Precepts of Palliative Care." *Last Acts*. (December 1997).

The workgroup decided to focus their recommendations of end-of-life care standards in two major areas – advance directives and palliative care.

RECOMMENDATIONS #4 AND #5 – ADVANCE DIRECTIVES

Many things, from the effects of a sudden injury to a terminal illness, can leave an individual incapacitated. Therefore, it is critical to have a method established to clearly convey the person's wishes for medical care in those situations when they are unable to communicate for themselves, when they become unable mentally to make decisions for themselves, or at the end of their life.

Advance directives can be part of the process of conveying one's wishes to loved ones and their physician. An advance directive is a formal document that can ensure that an individual's wishes will be honored. Along with the use of advance directives, it is important for the individual to discuss with loved ones and the physician their wishes and any concerns about the type and extent of medical care desired.

American Medical Association researchers found that “a program to increase the use of advance directives did not have an effect on the number of deaths reported by the participating nursing homes, nor did it affect the level of satisfaction with care reported by the participants in the program.” Furthermore, the study indicated “advance directives can communicate your preferences without decreasing your satisfaction with care.”

The workgroup discussed the standard three threshold criteria for withholding or withdrawal of life sustaining treatment contained in Chapter 765, Florida Statutes.

In August of 1999, the Panel for the Study for End of Life Care recommended dropping the requirement in Chapter 765, Florida Statutes, that the patient must be terminally ill, because it has been perceived as a barrier to withholding or withdrawal of life sustaining treatment in certain situations. Situations where patient advance directives or surrogates indicated treatment should be withheld or withdrawn but a physician refused to certify that the patient was terminally ill. During the 2000 Legislative session it became clear that an agreement could not be reached to drop “terminal” from Chapter 765, Florida Statutes.

As a compromise, an attempt was made to mitigate the terminal illness requirement from being a barrier to implementation of a patient's advance directive. “Persistent vegetative state,” which had already been added to the definition of terminal in the early nineties was separated from the definition of terminal illness, and made into an alternative threshold criterion for abatement of life sustaining treatment. In addition, another threshold criterion was added, “end stage condition,” with the idea that it would provide an option for patients who wished to refuse life support under circumstances when a physician might not certify them as terminally ill. It was proposed as a way of broadening the circumstances under which life support could be withdrawn or withheld.

Since the implementation of the 2000 End-of-Life Care legislation, a problem has been identified with the compromise language of “end stage condition” as another

threshold criterion to withhold or withdraw life-sustaining treatment in certain situations. In fact, a careful analysis of the definitions of these alternative threshold criteria reveals that they actually achieve the opposite of the intended effect. The definition of end stage condition actually turns out to apply to a narrower, rather than broader range of circumstances than the definition of terminal illness that has always been given in Chapter 765, Florida Statutes.

Two major reasons that these alternative threshold criteria achieve the opposite of the intended effect. First, the standard of clinical medical judgment to be applied in the definition of end stage condition is “reasonable medical certainty,” whereas the standard in the definition of terminal illness is “reasonable medical probability,” a substantially broader parameter. Secondly, and more importantly, the end stage condition definition allows treatment to be withheld or withdrawn only when treatment would be medically ineffective, whereas the definition of terminal illness would allow withholding or withdrawal of treatment when the patient can be expected to die without treatment.

In order to illustrate this difference it is useful to provide an example that reflects it clearly. For example, consider a Jehovah’s Witness who refused a blood transfusion in her advance directive, and was incapacitated and expected to die from loss of blood without a blood transfusion, then under the terminal illness definition, her refusal could be honored since she can be expected to die without treatment. Under the end stage condition definition, however, her refusal could not be honored, because she does not have a condition for which treatment would be medically ineffective. The same logic would apply to a patient whose advance directive refused an amputation.

In fact, if combined, in the two aspects of the narrower definition in end stage condition, a patient could not refuse chemotherapy in her advance directive until it were medically certain that the chemotherapy was ineffective. This would mean that the only treatment that could be refused by advance directive is physiologically futile treatment. This approach precludes patients from refusing medical measures that they would deem to be more burdensome than beneficial, even when these measures would ***probably, but not certainly, be medically ineffective***. By contrast, applying the definition of terminal would allow the same patient to refuse chemotherapy in an advance directive because ***a reasonable medical probability of recovery does not exist, and without treatment, the condition can be expected to cause death***. The three threshold criteria are printed below for reference with the points of contrast in bold italics. Chapter 765.101, Florida Statutes, states:

- (4) "End-stage condition" means a condition that is caused by injury, disease, or illness which has resulted in severe and permanent deterioration, indicated by incapacity and complete physical dependency, and for which, to a ***reasonable degree of medical certainty, treatment of the irreversible condition would be medically ineffective***.
- (12) "Persistent vegetative state" means a permanent and irreversible condition of unconsciousness in which there is:
 - (a) The absence of voluntary action or cognitive behavior of any kind.
 - (b) An inability to communicate or interact purposefully with the environment.

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

A number of practical problems result from these three threshold criteria. A positive result of these criteria is when correctly understood, the definitions are broad enough not to constitute a barrier to withholding or withdrawal of life sustaining treatment under any circumstances in which the patient can be expected to die. The definitions are more consonant with the application of the Florida Supreme Court's decision in re: Guardianship of Estelle M. Browning, State of Florida, Petitioner, v. Doris F. Herbert. Although the Court's overall ruling arguably holds that "terminal condition" as a mandatory threshold criterion is unconstitutional, they apply an analysis of terminal condition to Estelle Browning's case, because her advance directive stated terminal illness as a condition of her refusal of treatment, and in fact it also required that death be imminent. Although the trial court had established that she might live months or years in a persistent vegetative state (this occurred prior to persistent vegetative state being a threshold criterion in Chapter 765, Florida Statutes), the court determined that she met the conditions of terminally ill and imminent death as explained in the following two paragraphs from the decision.

"The trial court found that death would occur within four to nine days after removal of the nasogastric feeding tube. Therefore, Mrs. Browning's life could only have been sustained beyond that time by the administration of artificial intrusive measures."

"Under those circumstances, Mrs. Browning's death was imminent as we construe her express written intent. In addition, all the doctors agreed that Mrs. Browning suffered permanent brain damage and the medical testimony established that there was no hope that she would recover from her condition. We are satisfied that clear and convincing evidence existed to support a finding that *Mrs. Browning suffered from a terminal condition*. Under these circumstances, the surrogate was correct in instructing Mrs. Browning's health care providers to discontinue all life-sustaining procedures in accordance with Mrs. Browning's wishes."

Although Chapter 765, Florida Statutes, definition of terminal is very broad, it is broader than the way many providers use it in ordinary clinical contexts. Providers often use terminal to refer primarily to incurable conditions. In this sense terminal is used as an adjective to distinguish cancer that can no longer be treated, or AIDS, which is ultimately fatal. That is not to say that the concept of terminal has a clear scientifically established, universally observed definition; much less a reliable diagnostic test. The problem with using a term that is used widely but imprecisely in clinical usage is that many use it without regard to the broad definition given to it in the Florida Statutes.

This problem exists, not only for clinicians' interpretations of "terminal," but for patients as well. Whether terminal is defined broadly, as in Chapter 765, Florida Statutes, or even if it were dropped from the Statute altogether (or stricken by the Florida Supreme Court as unconstitutional), the majority of Floridians' canned advance directives would

probably still contain the term, and it is not at all clear that they were aware of the statutory definition when they executed their form. Nor is it clear what meaning they attached to “terminal” along the continuum of meanings.

Thus, if we are to have to abide by such threshold criteria as are embodied in Chapter 765, Florida Statutes, we have an overwhelming educational task in order to ensure that clinicians who advise patients, and apply their advance directives, and patients who are completing them understand the distinctions among the three alternatives well enough to choose among them. The persistent vegetative state alternative seems to be compatible as an augmentation to terminal condition, so that both of them could be chosen without conflict. However, choosing end stage condition and terminal condition would be incompatible. Arguably, choosing end stage condition is in conflict with persistent vegetative state. Moreover since, persistent vegetative state, was pulled out from the prior definition of terminal had no standard of medical judgment added to it, such as probability or certainty in the other two alternatives. Having these three criteria arguably increases the range of choices for patients to determine their own care at the end of life, but can we provide adequate and effective instruction to intelligibly utilize these distinctions without an unacceptable level of confusion among both patients and providers. If we can forge standards around which consensus can be built, we may be able to substantially reduce such confusion, but the magnitude of this task should not be underestimated.

The workgroup’s specific recommendation #4 is:

- To add best interest to Chapter 765, Florida Statutes as follows:

Substituted judgment must be the preferred standard of decision-making used by health surrogates, durable powers of attorney for health care, and proxy decision-makers, but when there is no indication what the principal would have chosen, proposed or currently in effect, treatments may be withheld or withdrawn by the surrogate, durable powers of attorney for health care, or proxy’s decision under a best interest standard.

The workgroup’s specific recommendation #5 is:

- To delete from Chapter 765, Florida Statutes, the threshold alternative criteria required to be certified in order to withhold or withdraw life-sustaining treatment.
- If the above criteria is not omitted, “end stage condition” definition should be changed to read as follows:

Section 765.101(4), Florida Statutes, End stage condition means a condition that is caused by injury, disease, or illness which has resulted in progressively severe and permanent deterioration, and for which the patient, resident, or authorized representative would deem life-prolonging treatment to be more of a burden than a benefit.

RECOMMENDATION #6 – PALLIATIVE CARE

In Florida, the lack of a definition and common understanding of palliative care and its role in the health care continuum contributes to the underutilization of these services and to unnecessary suffering that many Floridians experience in the last stages of life. Adoption of a formal definition of palliative care in Florida Statute should foster greater understanding, acceptance, and more timely application of services and referral of appropriate patients. Palliative care affirms life, and regards dying as a natural process that is a profoundly personal experience for the individual and family. The Last Acts Organization has stated that “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.”

The workgroup’s specific recommendation #6 is:

There is a continued need to address the quality and availability of humane care for all Floridians who die each year in our state’s hospitals, nursing homes and communities. In an effort to improve care the workgroup recommends the following:

- To add the following definition of palliative care, which was adopted by Palliative Care Task Force of Last Acts Organization in December 1997, to Chapter 765, Florida Statutes:

“Palliative care refers to the comprehensive management of the physical, psychological, social, spiritual, and existential needs of patients. It is especially suited to the care of people with incurable, progressive illness.”

Source: Task Force on Palliative Care. “Precepts of Palliative Care.” Last Acts. (December 1997).

RECOMMENDATION #7 – ACCESS TO END-OF-LIFE AND PALLIATIVE CARE

Access to comprehensive end-of-life and palliative care services across the spectrum of health care settings is limited. There is a need for all health care organizations serving seriously ill and dying patients to ensure availability of end-of-life, palliative, and hospice care services.

Increasing access to end-of-life and palliative care services across the full spectrum of health and long term care settings will promote high quality of care for dying patients in Florida. All health and long term care organizations should review their internal organizational strengths and weaknesses with regard to the quality of end-of-life and palliative care services offered. Efforts to improve quality of end-of-life, palliative, and hospice care services should be included in an organization’s quality improvement programs. The workgroup also recognizes the need to ensure access to end-of-life and palliative care services for many Floridians including those uninsured, those living in rural areas and among culturally distinct populations. Removing administrative and regulatory barriers to end-of-life, palliative, and hospice care services is essential to improve access to these services.

The workgroup’s specific recommendation #7 is:

- To increase access to end-of-life and palliative care, add the following proposed language to Chapter 765, Florida Statutes:

State health and long term care organizations and individual health and long term care entities should evaluate:

- (a) The adequacy of their end-of-life and palliative care services including cultural appropriateness;
- (b) The relevant reimbursement policies which ensure availability of end-of-life and palliative care; and
- (c) Applicable administrative and regulatory barriers to end-of-life and palliative care.

RECOMMENDATION #8 – PALLIATIVE CARE STANDARDS

The workgroup determined that the Florida Statutes do not provide quality of care standards for end-of-life care. The workgroup identified the standards developed by the American Medical Association (AMA) called “Elements of Quality Care for Patients in the Last Phase of Life” as comprehensive and in concert with quality of care standards already provided for in other parts of Florida Statutes. Establishing a comprehensive set of standards under the heading of palliative care will promote more comprehensive efforts to improve and monitor end-of-life care services. A new community standard can thus be established.

The workgroup’s specific recommendation #8 is:

- To add the following standards to Chapter 765, Florida Statutes.

Palliative care must include an:

- 1) Opportunity to discuss and plan for end of life care.
- 2) Assurance that physical and mental suffering will be carefully attended to.
- 3) Assurance that preferences for withholding and withdrawing life-sustaining interventions will be honored.
- 4) Assurance that the personal goals of the dying person will be addressed.
- 5) Assurance that the dignity of the dying person will be a priority.
- 6) Assurance that health care providers will not abandon the dying person.
- 7) Assurance that the burden to family and others will be addressed.
- 8) Assurance that advance directives for care will be respected regardless of the location of care.
- 9) Assurance that organizational mechanisms are in place to evaluate the availability and quality of end-of-life and palliative care services.
- 10) Assurance that necessary health care services will be provided.
- 11) Assurance that the above will be done in culturally appropriate manner.

Source: AMA “Elements of Quality Care for Patients in the Last Phase of Life”.

Listed Table 3 is an index of the quality of care Florida Statutes cross-referenced with the AMA “Elements of Quality Care for Patients in the Last Phase of Life”. Details regarding the relevant end-of-life care Florida administrative rules are available upon request from the Agency for Health Care Administration.

TABLE 3 Elements of Quality Cross Referenced In Florida Statutes	
1. Opportunity to discuss and plan for end of life care.	<ul style="list-style-type: none"> • <u>Public Health</u>: s. 381.026(6), F.S., Florida Patient’s Bill of Rights and Responsibilities. • <u>Nursing Homes</u>: s. 400.022(1)(j) & (l), F.S., Resident Rights. • <u>Assisted Living Facilities</u>: s. 400.428(1)(j), F.S., Resident Bill of Rights. • <u>Home Health Agencies</u>: s. 400.487(4), F.S., Home health service agreements; physician’s treatment orders; patient assessment; establishment and review of plan of care; provision of services; orders not to resuscitate. • <u>Hospices</u>: s. 400.6095, F.S., Patient Admission; assessment; plan of care; discharge; death.
2. Assurance physical and mental suffering will be carefully attended to.	<ul style="list-style-type: none"> • <u>Hospitals and Other Licensed Facilities</u>: s. 395.1055(2), F.S., Rules and enforcement. • <u>Nursing Homes</u>: s. 400.022(1)(l), F.S., Resident Rights. • <u>Assisted Living Facilities</u>: s. 400.441(2)(m)(h), F.S., Rules establishing standards. • <u>Home Health Agencies</u>: s. 400.497(7), F.S., Rules establishing minimum standards. • <u>Hospices</u>: s. 400.6095(1), F.S., Patient Admission; assessment; plan of care; discharge; death.
3. Assurance preferences for withholding and withdrawing life-sustaining interventions will be honored.	<ul style="list-style-type: none"> • <u>Health Care Advance Directives</u>: s. 765.1105, F.S., Transfer of a patient. • Withholding or Withdrawing CPR: ss. 395.1041, 400.142, 400.4255, 400.487, 400.6095, 400.621, and 401.45.
4. Assurance the personal goals of the dying person will be addressed.	<ul style="list-style-type: none"> • <u>Public Health</u>: s. 381.026(4)(a)(1) & (6), F.S., Florida Patient’s Bill of Rights and Responsibilities. • <u>Nursing Homes</u>: s. 400.022(1)(n), F.S., Resident Rights. • <u>Assisted Living Facilities</u>: s. 400.428(1)(b), F.S., Resident Bill of Rights. • <u>Home Health Agencies</u>: s. 400.487(6), F.S., Home health service agreements; physician’s treatment orders; patient assessment; establishment and review of plan of care; provision of services; orders not to resuscitate. • <u>Hospices</u>: s. 400.6005, F.S., Legislative findings and intent.
5. Assurance the dignity of the dying person will be a priority.	<ul style="list-style-type: none"> • <u>Public Health</u>: s. 381.026(4)(a)(1) & (6), F.S., Florida Patient’s Bill of Rights and Responsibilities. • <u>Nursing Homes</u>: s. 400.022(1)(n), F.S., Resident Rights. • <u>Assisted Living Facilities</u>: s. 400.428(1)(b), F.S., Resident Bill of Rights. • <u>Home Health Agencies</u>: s. 400.487(6), F.S. • <u>Hospices</u>: s. 400.6005, F.S., Legislative findings, intent.

TABLE 3 (Continued) Elements of Quality Cross Referenced In Florida Statutes	
6. Assurance health care providers will not abandon the dying person.	<ul style="list-style-type: none"> • <u>Medical Practice</u>: s. 458.331(2)(t), F.S., Grounds for disciplinary action; action by the board and department.
7. Assurance the burden to family and others will be addressed.	<ul style="list-style-type: none"> • <u>Hospices</u>: s. 400.6095(1), F.S., Patient Admission; assessment; plan of care; discharge; death.
8. Assurance advance directives for care will be respected regardless of the location of care.	<ul style="list-style-type: none"> • <u>Health Care Advance Directives</u>: s. 765.110(2), F.S., Health care facilities and providers; discipline. • <u>Do Not Resuscitate Order</u>: s.401.45, F.S.
9. Assurance organizational mechanisms are in place to evaluate the availability and quality of palliative care services.	<ul style="list-style-type: none"> • Health Care Advance Directives: s. 765.1103(2), F.S., Pain management and palliative care.
10. Assurance necessary care and services are provided.	<ul style="list-style-type: none"> • Chapter 395, F.S., Hospitals and Other Licensed Facilities • Chapter 400, Part II, F.S., Nursing Homes • Chapter 400, Part III, F.S., Assisted Living Facilities • Chapter 400, Part IV, F.S., Home Health Agencies • Chapter 400, Part VI, F.S., Hospices

RECOMMENDATION #9 – DEMONSTRATION PROJECT

The workgroup determined that there is a need to fund research and demonstration projects to: 1) promote improved access to end-of-life care especially among uninsured and culturally distinct populations; and 2) evaluate through a demonstration project evidence-based approaches to improve end-of-life and palliative care. As demonstrated by the Robert Wood Johnson Foundation recent report called “Pioneer Programs in Palliative Care: Nine Case Studies”, innovative clinical programs with creative reimbursement strategies are being developed nationally. The Legislature has provided authority to the Department of Health to develop and implement a demonstration project for end-of-life care. Funding for a demonstration project could be provided from grants and the legislature. Programs such as the Balm of Gilead Center in Alabama that are budget neutral should be developed.

The workgroup’s specific recommendation #9 is:

- To initiate a demonstration project that would:
 - (a) Identify current research relevant to end-of-life and palliative care in Florida communities with attention to be given to research dealing with culturally distinct populations;
 - (b) Enhance quality and access to end-of-life and palliative care services especially in rural, uninsured and minority communities;
 - (c) Develop collaborative research and demonstration partnerships; and
 - (d) Disseminate the results of current research using culturally appropriate mechanisms.

RECOMMENDATION #10 – END-OF-LIFE CARE STANDARDS EDUCATION

Training and education on end-of-life care will assist the patient, patient's families, and professionals confronting end-of-life care issues. Training the public, especially those acting as health care surrogates or proxies for incapacitated individuals will promote more informed decision makers. Public and private funding sources should be sought, in order to afford educational tools necessary to educate the public on end-of-life care. An example of an existing public education program that might be used as a model for creating a volunteer public education program is the Department of Elder Affairs "SHINE Program".

The workgroup determined that there is an urgent need to improve awareness, knowledge, and skills in end-of-life and palliative care for health care consumers and providers alike.

The workgroup's specific recommendation #10 is:

- To promote public and professional education in end-of-life care standards, add to Chapter 765, Florida Statutes.

A. Public

- 1) The appropriate state agency will identify and coordinate existing training programs and materials on end-of-life and palliative care that would be available in all communities and collaborate with programs such as Robert Wood Johnson Foundation Partnership for End-of-Life Care Grant to promote community awareness and skills of surrogate and proxy decision makers. The agency will determine the need for and establish new programs on training of surrogate and proxy decision makers that includes cultural values, beliefs and practices to ensure ongoing programs meet community needs. The program components should include:
 - a) Consumer choices and responsibilities,
 - b) Culturally appropriateness and linguistically diversified,
 - c) Expectation for access to effective pain management and palliative care in all health care settings,
 - d) Advance Directives and Surrogate/Proxy decision makers, and
 - e) Targeting elders, their children, and caregivers in a public relations effort to improve their decision-making.

B. Professional

- 1) Encourage educational institutions to establish or enhance curricula to rapidly improve training in palliative care for physicians, nurses, counselors, social workers, pharmacists, or any other end-of-life care provider.
- 2) Encourage the use of established professional curricula in Continuing Medical Education (CME) and Continuing Education Unit (CEU).
- 3) Encourage the development of palliative medicine fellowship program in the four medical schools in the state.
- 4) Encourage the inclusion of culturally appropriate materials.

Non-Concurring and Individual Opinions

This section includes workgroup members non-concurring and individual opinions.

FOCUS ON YOUR FAILURE AND SEEK TO CORRECT IT

My first mentor in Acupuncture and Oriental medicine, (Dr. Robert C. Sohn, Florida Acupuncture Physician and PhD), taught.....always focus on your failure and seek to correct it. Then, that which is positive in you will manifest and grow. If, however, you focus on your positive side and bask in the glory of it, the rest of what you are will freely manifest in its pain, its suffering, its jealousy, its ugliness, its rage, its fear, its laziness, and its incompetence. And you will deteriorate more and more.

Looking at what you have done instead of what you have failed to do is like a man walking backwards along a dangerous path; he is bound to be severely injured. If you cannot find something wrong with your actions then you have not looked hard enough. There is always room for correction and expansion.

Throughout the minutes of each meeting the reader will find the progression of Recommendation #5 of the Reimbursement Task Force which is stated on Page 71 as.....*Recognize health care professionals licensed under Chapter 457, 458, 459, 460, and 464, F.S., providing end-of-life care services, and reimburse them under the state Medicaid methodologies and insurance plans, in accordance with sections 627 and 641, F.S.*

On November 27, 2000 extensive documentation was presented, by the Florida State Oriental Medical Association, to the full Task Force at the request of Marshal Kelley. A majority of the Task Force vetoed the proposed motion without ever reviewing any of the documentation requested and provided.

It is the hope that the Florida legislature will avail themselves of the documentation provided, to the Department of Elder Affairs and the EOL Workgroup, and consider the recommendation which was drafted in order to fulfill the directive of *enabling all health providers along the health care continuum to participate in an excellent system of delivering end-of-life care*.

Richard A. Freiberg, DOM, DAc, DiplAc
Florida State Oriental Medical Association - Legislative Chair

Appendix A: Member Listing and Biographical Sketches

Member Organization	Member
Agency for Health Care Administration	Susan Acker, Ph.D. Managed Care and Health Quality Agency for Health Care Administration 2727 Mahan Drive, Building 1, Room Tallahassee, Florida 32308- Phone: (850) 413-7201 FAX: (850) 414-6946 E-mail: ackers@fdhc.state.fl.us
Department of Elder Affairs	Gema G. Hernandez, D.P.A. Secretary, Department of Elder Affairs Marshall E. Kelley, Director Statewide Community Based Services E-mail: Kelleyme@elderaffairs.org Linda Macdonald, M.S., Statewide Community Based Services 4040 Esplanade Way, Suite 315 Tallahassee, FL 32399-7000 Phone: (850) 414-2113 E-mail: macdonaldla@elderaffairs.org
Department of Health	Freida B. Travis, Senior Management Analyst II Bureau of Emergency Medical Services Department of Health (DOH) 4052 Bald Cypress Way, Bin C 18 Tallahassee, FL 32399-1738 Phone: (850) 245-4440 FAX: (850)487-2911 E-mail: freida_travis@doh.state.fl.us
Florida Assisted Living Association	Henry Pearson Pearson Rest Home and Florida Assisted Living Association 2928 McQueens Road Apopka, FL 32703 Phone: (407) 886-4055 FAX: (407) 886-9784 E-mail: sirhenry@iag.net
Member Organization	Member
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Maintenance Organizations

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Florida Association of Homes for the Aging

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Florida Health Care Association

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Member Organization

Member

Florida Hospital Association

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Member Organization

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Florida Pharmacy Association

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Florida State Oriental Medical Association

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BIOGRAPHICAL SKETCHES

Susan Acker, Ph.D

Agency for Health Care Administration

Dr. Susan Acker is with the Agency for Health Care Administration, Division of Health Quality Assurance. She is currently the Supervisor of the Health Standards and Quality Unit and the Agency's expert witness on long-term care and the survey process. Dr. Acker has been with the Division since 1987. Member.

Samira K. Beckwith

Florida Hospices and Palliative Care, Inc.

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.

Joanne L. Bujnoski, D.O.

Florida Osteopathic Medical Association

Dr. Joanne L. Bujnoski, D.O., is a board certified radiation oncologist. She is Medical Director of the James H. Baroco Center for Cancer Care at Sacred Heart Hospital, Pensacola, Florida, and is President of South Alabama Radiation Oncology. She is on the Board of Directors for the Florida Osteopathic Medical Association and Chairperson of the Medical Economics Committee of the Escambia County Medical Society. Member.

Cathy Emmett, A.R.N.P.

Florida Nurses Association

Ms. Emmett has been a nurse for 20 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 Geriatrics Nurse Practitioner and certified Hospice and Palliative Care Nurse. Member.

Richard A. Freiberg, DOM, D.Ac. Dipl.Ac.

Florida State Oriental Medical Association

Dr. Freiberg is an active licensed acupuncture physician, a doctor of Acupuncture in Rhode Island, holds an active diplomat in Acupuncture nationally (is actively board certified by NCCAOM). He is also a certified acupuncture physician for Florida Workers Compensation. He is currently the Legislative Chair for the Florida State Oriental Medical Association, and a member of the Broward County Medical Association Alternative Medicine Committee. Dr. Freiberg received his Doctor of Oriental Medicine degree from the Medicina Alternativa Institute in Sri Lanka following extensive postgraduate work. Member.

Gema G. Hernandez, D.P.A.

Secretary, Department of Elder Affairs

Dr. Hernandez was appointed the Secretary of the Florida Department of Elder 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.

Julia H. Herndon, LUTCF, HIA Consultant

Florida Association of Insurance & Financial Advisors

Mrs. Herndon has been in the employee benefits business since 1981 and has attained her LUTCF (Life Underwriters Training Council Fellowship) and HIA (Health Insurance Associate) designation and is now working toward her REBC. These designations represent years of dedication and study to enhance Mrs. Herndon's knowledge of the employee benefits industry. She is past President of the Tallahassee Lifer Underwriters Association and is currently the President-Elect of the Capital Area Health Underwriters Association. She has been a Moderator/instructor for the Life Underwriters Classes, continuing education classes for Tallahassee Community College, and the Tallahassee Association of Life Underwriters. Member.

Marshall E. Kelley

Department of Elder Affairs

Marshall E. Kelley directs the Division of Statewide Community Based Services within the Florida Department of Elder Affairs. Mr. Kelley has 30 years of experience in health, education and social services programs in Florida. He has served as the Medicaid Director, Director of Health Quality Assurance, and managed services, operations in the Department of Education for Federal Higher Education Financial Assistance programs and 18 years in a number of professional positions in the Florida Department of Health and Rehabilitative Services in Tampa, Gainesville and Tallahassee. A native of Tampa, he holds a master's degree in government administration from Georgia State University, a master's degree in U.S. history and political science from Indiana University and a bachelor's degree in history from the University of South Florida. Member.

The Honorable Ron Klein

Florida Senate

State Senator Ron Klein is currently serving his fourth term in the Florida Senate. He was elected to the Senate in 1996 after serving four years in the Florida House of Representatives. As a member of the Senate Committee on Health, Aging and Long-Term Care and a former member of the Panel for the Study of End-of-Life, Senator Klein sponsored Senate Bill 1890 (2000) and Senate Bill 2228 (1999) - ground breaking legislation which addressed the challenges of delivering appropriate end-of-life care services while providing health care choices for individuals at the end of life. He continues to work toward educating both the public and Florida's health care practitioners in creating quality end of life experiences. Member.

Henry Pearson

Florida Assisted Living Association

Mr. Pearson is the Administrator at Pearson's Rest Home in Apopka, Florida. He has been an Assisted Living Caregiver for over 24 years. He is a member of the Florida Assisted Living Association, and was the President of the Association's East Central Chapter from 1997 - 2000. He was formerly the Chairman of the Membership Committee for FALA, and still retains a position on the Association's Board. Member.

James Powers

Florida Pharmacy Association

Mr. Powers is a retired pharmacist, who has served as a narcotic agent for the state of Florida and also as a senior pharmacist in the Agency for Health Care Administration, Florida Medicaid Program. Mr. Powers has served as the Executive Vice President of the Florida Pharmacy Association for 21 years and also is a past president of the association. Member.

Marshall Seiden

Florida Association of Homes for the Aging

Mr. Seiden is the Chief Executive Officer 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 31 year career, he has held executive positions in several prominent long term care and hospital settings. He has served as Vice Chairman of the Florida Association of Homes for the Aging and in several voluntary professional, governmental, and community positions. At Menorah Manor he has developed a Jewish Hospice Program, a major Alzheimer's disease program, medical and allied health teaching affiliations, a comprehensive adult day health care center, and specialty geriatric clinical services. Member.

Alvin E. Smith, M.D.

Florida Medical Association

Dr. Smith is a retired medical oncologist who has been involved in activities surrounding End of Life Issues since 1986. He is a past President of the Florida Medical Association and the Florida Division of the American Cancer Society, as well as the Chair of the Florida State Commission on Pain. Presently a member of the Cancer Control and Research Advisory Council and the Board of Directors of Project Hope. Previously a member of the Florida Commission on Aging with Dignity and is an Adjunct Professor of Political Science at Stetson University with a special interest in Health Policy in the United States. Member.

Peg Terbeek

Florida Life Care Residents Association, Inc.

Mrs. Terbeek is a resident of John Knox Village of Orange City, a Continuing Care Retirement Community. She serves as Chairperson of the JKV Wellness Program and the Fitness Center Committees, Secretary of the JKV Bioethics Committee, Member of the Board of Directors of Project GRACE, and member of the Board of Directors of both the State and JKV FliCRA. Member.

Freida Travis

Department of Health

Freida Travis is the Administrator for the Operations Section within the Bureau of Emergency Medical Services, Division of Emergency Medical Services/Community Health Resources, and FL Department of Health. She is a certified emergency medical technician and has 25 years of experience with the Bureau of EMS in a variety of positions. She is responsible for activities, which are designed to strengthen existing pre-hospital programs or develop new ones including medical direction/quality assurance, EMS communications capability, EMS matching, county and rural grants, pre-hospital/hospital data collection, and Do Not Resuscitate Orders (DNROS). Ms. Travis served as an advisor to the End-of-Life Care Panel created in 1998, and has conducted numerous workshops on DNR Orders and made many presentations throughout the State. Member.

Howard Tuch, M.D.

Florida Health Care Association

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.

Susan V. White, Ph.D.,

Florida Hospital Association

Susie White, Ph.D., Vice President / Quality Management, joined the Florida Hospital Association staff in 1997. Prior to this position she has over twenty years of experience in the health care field in administration, management, and clinical roles. She has experience as Associate Executive Director and Director of Nursing in a community hospital and developed the quality management program for a hospital within a large network. Dr. White has health care experience in a variety of acute care settings including clinical, administrative, and informatics. Her responsibilities include JCAHO related activities, resources on quality initiative, patient safety, initiatives on clinical performance improvement and patient perception, educational programs, and newsletters. Dr. White is a fourth year Sterling Examiner for the Florida Sterling Council and on the faculty at the University of Phoenix. She has been certified in various specialties to include certification in critical care nursing, nursing administration and health care quality. She holds a M.S.N. and Ph.D. from the University of Florida. Member.

Sharon Zill, PhD

Florida Association of Health Maintenance Organizations

Sharon Zill, PhD is Director of Over 65 Market for Blue Cross Blue Shield of Florida and responsible for strategic planning and marketing senior products. Prior to joining Blue Cross of South Florida, Ms. Zill was Associate Dean of Finance and Administration at the University of Colorado School of Nursing and an Assistant Professor; and a Manager of Health Care Consulting for Ernst & Young LLP. Ms. Zill is a Geriatric Nurse Practitioner and performs research at the University of Texas on Cost/Quality trade offs in geriatric clinical care. She has been a speaker at numerous conferences on elder care and financing issues. Member.

Appendix B: End-of-Life Care Workgroup Meeting Summaries

END-OF-LIFE CARE WORKGROUP MEETING SUMMARY

Monday, August 28, 2000

Room 225F, Department of Elder Affairs, 4040 Esplanade Way,
Tallahassee, Florida 32399-7000

Workgroup Members in Attendance

Susan Acker, Agency for Health Care Administration (AHCA)
Samira Beckwith, Florida Hospices and Palliative Care, Inc. (FHPC)
Bill Bell, Florida Hospital Association (FHA) for Susan White, M.D., Member
Dr. JoAnne Bujnoski, Florida Osteopathic Medical Association (FOMA)
Cathy Emmett, ARNP, Florida Nurses Association (FNA)
Richard Freiberg, D.O.M., D.Ac., Dipl.Ac., Florida State Oriental Medical Association (FSOMA)
Gema G. Hernandez, D.P.A., Secretary, Department of Elder Affairs (DOEA)
Julia Herndon, Florida Association of Insurance and Financial Advisors (FAIFA)
Marshall Kelley, Department of Elder Affairs, **Facilitator**
Senator Ron Klein, Florida Senate
Linda Macdonald, Department of Elder Affairs (DOEA)
George Mayzell, M.D., Fla. Association of Health Maintenance Organization (FAHMO)
Henry Pearson, Florida Assisted Living Association (FALA)
Marshall Seiden, Florida Association of Homes for the Aging (FAHA)
Alvin E. Smith, M.D., Florida Medical Association (FMA)
Peg Terbeek, Florida Life Care Residents Association (FLiCRA)
Freida B. Travis, Department of Health (DOH)
Howard Tuch, M.D., Florida Health Care Association (FHCA)
Peggy Ann Zaenger, Florida Pharmacy Association (FPA)

Observers in Attendance

Bill Allen, J.D., M. Div., Associate Professor, University of Florida, Bioethics, Law and the Humanities Program; and the Florida Bioethics Network
Wanda Carter, Senior Legislative Analyst, Senate Health, Aging, Long-Term Care Committee
Michael Crawford, Department of Elder Affairs
Debra Gressel, Florida Association of Homes for the Aging
Eric Haug, Department of Elder Affairs
Danielle Hopkins, Florida Hospices and Palliative Care, Inc.
Lynn Mulder, Florida Hospices and Palliative Care, Inc.
Tom McMullen, Department of Elder Affairs
Bennett Napier, Florida Life Care Residents Association, Inc.
Koko Okano, Florida Health Care Association
Madeline Smith, Department of Elder Affairs
Jessica Swanson, Department of Health

Support Staff in Attendance: Kathi Chisolm, Beverly Friedberg, Mary Hodges, Veronica Johnson, and Ann Wagner, Department of Elder Affairs

Call to Order

The meeting was called to order at 10:00 a.m. by Marshall Kelley, Director of Statewide Community Based Services in the Department of Elder Affairs. Mr. Kelley welcomed members, reviewed the meeting agenda, and read the **workgroup's mission** outlined in Section 16 of Chapter 295-2000, Laws of Florida which states:

“Section 16. End-of-Life Care Workgroup –

(1) There is created within the Department of Elder Affairs the End-of-Life Care Workgroup. The workgroup shall:

- a) Examine reimbursement methodologies for end-of-life care;
- b) Identify end-of-life care standards that will enable all health providers along the health-care continuum to participate in an excellent system of delivering end-of-life care; and
- c) Develop recommendations for incentives for appropriate end-of-life care.”

Mr. Kelley introduced Dr. Gema Hernandez, D.P.A., the Secretary for the Department of Elder Affairs as the *opening speaker*. Dr. Hernandez spoke about the importance of the workgroup and issues she deems as critical for the workgroup to review.

- ✓ Cultural competency, religious beliefs and spirituality sensitivity for end-of-life care;
- ✓ Quality of life at the end-of-life;
- ✓ Affordable and accessible end-of-life care in the continuum of care;
- ✓ Accessibility of end-of-life care in rural communities;
- ✓ Challenge the committee to provide and encourage public testimony to the Long-Term Care Committee on end-of-life issues; and
- ✓ Identify training needs for doctors to provide palliative care.

Issues raised by Dr. Hernandez's presentation included:

- Need for physicians training on end-of-life care issues;
- Need for appropriate statute changes regarding physician liability issues as it relates to providing end-of-life care; and
- Dr. Hernandez stated Senator McKay is working on long-term care liability concerns for nursing homes and that she is also recommending that the Affordability Task Forces look at the continuum of long-term care issues, including end-of-life care issues.

Mr. Kelley asked that each workgroup member introduce himself or herself by providing a brief summary of their own expertise regarding end-of-life care. After the introductions, Mr. Kelley reviewed the contents of the workgroup member notebooks.

Then, Mr. Kelley indicated that there would be three speakers to provide brief summaries of end-of-life care activities. The three speakers are Freida Travis, Susan Acker, and Samira Beckwith. Mr. Kelley asked Freida Travis to provide the first presentation to the workgroup.

Freida Travis from the Department of Health presented an overview of activities related to the Do Not Resuscitate Order (DNRO). Ms. Travis provided an historical context of the DNRO and reviewed current legislation. Ms. Travis presented to the workgroup members a copy of Emergency Medical Services DNRO Form # 1896 dated February 2000; the March 2000 letter from the Department of Health to health care facilities personnel transmitting the form; and copies of slide presentation materials used to train emergency medical personnel on the issue.

Marshall Kelley thanked Ms. Travis and introduced the second speaker, Dr. Susan Acker.

Dr Susan Acker from the Agency for Health Care Administration presented an overview of the standards for end-of-life care. Dr. Acker reviewed the standard of care for end-of-life care. Dr. Acker provided handouts including: a summary of recent activities, Ten Quality Domains for Care at the End-of-Life, Eleven Principles for End-of Life Care, and copies of slide presentation materials used to train on the issue. Dr. Acker suggested that workgroup members add these handouts to their notebooks.

Marshall Kelley thanked Dr. Acker for her presentation. Mr. Kelley asked the workgroup members to start thinking about which small group (standards of care task force or reimbursement task force) they would like to participate in during the afternoon session. Mr. Kelley asked that the workgroup break for lunch from 12:15 p.m. and reconvene at 1:15 p.m.

At 1:15 p.m. the End-of-Life Care Workgroup reconvened. Marshall Kelley introduced the third speaker, Samira Beckwith.

Samira Beckwith from the Florida Hospices and Palliative Care, Inc. presented an overview of end-of-life care reimbursement activities. Ms. Beckwith discussed reimbursement issues as it relates to end-of-life care. Ms. Beckwith stated that 25% of Medicare payments are made in the last year of life. She suggested the workgroup members identify gaps in care and make recommendations to improve end-of-life care. Ms. Beckwith needs to identify where patients are cared for now and how they are reimbursed. Ms. Beckwith asked the workgroup to consider “What are the incentives/barriers to good end-of-life care?” She pointed out that payment for medications for symptoms and pain management is a serious concern. Another question she asked was “What are the factors/rules that influence care?” Example provided to the workgroup was that IV therapy is ordered to justify hospitalization. The discussion of uncovered services included the following items:

- 1) Attendant care for people without a caregiver
- 2) Outpatient drugs
- 3) Aid services
- 4) Respite services
- 5) Planning physician visits

The discussion ended with the suggestion that workgroup members may want to review the new medication law.

Mr. Kelley thanked Ms. Beckwith for her presentation. Mr. Kelley then provided a summary of the morning session. Mr. Kelley stated that he knew the workgroup was interested in all of

the issues and asked for a show of hands who wanted to split into the three groups - reimbursement, standards and recommendations for incentives for appropriate end-of-life care. After a show of hands, it was decided to have only two small task force groups with both developing recommendations for incentives for appropriate end-of-life care. Mr. Kelley stated the group may need other expertise not here today and asked the group to let DOEA know of issues, other expertise needed and other materials needed. Samira Beckwith recommended the next meeting time and place be established in the event some members had to leave early. Several dates were discussed with a the following agreement by workgroup members:

- ✓ **September 22, 2000**, from 10:00 a.m. to 3:00 p.m. will be held in Tallahassee; and
- ✓ **October 16, 2000**, from 10:00 a.m. to 3:00 p.m. the location of this meeting is yet to be agreed upon.

Mr. Kelley asked that the workgroup members officially notify DOEA if and where they would like to hold the October 16 workgroup meeting. Mr. Kelley reminded the workgroup that a report must be submitted to the Legislature by December 31, and that DOEA, within existing resources, is providing staff support to the workgroup. Mr. Kelley pointed out that DOEA would not be able to provide as much staff support to the workgroup if meetings are held outside of Tallahassee.

Mr. Kelley then asked for the two task force groups to meet and reconvene in the large workgroup at 2:45 p.m. Mr. Kelley asked each task force to develop a list of issues related to their topic area. One task force was asked to review the reimbursement for end-of-life care; and the other task forces was asked to review standards for end-of-life care. Both task forces were asked to develop recommendations for incentives for appropriate end-of-life care.

To assist the small task forces, a handwritten list of the issues identified in the morning session was distributed, along with copies of the draft Work Plan for workgroup.

The issues identified during the large workgroup session are as follows:

- Use of the word “may” on the DNRO. Is the DNRO considered an order, advance directive, or living will? Also, the validity of the form;
- Form requiring second opinion - terminal condition - refers to statute;
- National Registry;
- Asking the workgroup members to provide for testimony possible through their memberships to the Long-Term Care Committee on end-of-life care issues;
- Cultural/Minority issues;
- Availability of palliative care in rural areas;
- 11 Principles of End-of-Life Care and 10 Quality Domains for End-of Life Care;
- Establish a more definitive procedure to accept oral advance directives such as a note witnessed by nursing home employee;
- Standard of care from two perspectives that include a) health care practitioner and b) health care facilities; and
- Affordable and accessible end-of-life care in the continuum of care.

The large workgroup reconvened at 2:45 p.m. Mr. Kelley provided a summary of the meeting. DOEA will get the lists of issues from both small task forces and provide copies to the workgroup members. DOEA staff provided copies of the minutes of the previous Panel for the Study for End-of-Life Care. Mr. Kelley thanked the workgroup members for their work and stated that all business is to be conducted within the Sunshine law and open to public. Dr. Tuch suggested all members bring additional materials with them to the next meeting so they can be prepared to make the most of their time together. Mr. Kelley closed the meeting at 3:00 p.m.

REIMBURSEMENT TASK FORCE MEETING SUMMARY

Monday, August 28, 2000 from 1:30 p.m. to 2:45 p.m.

Room 235M, Department of Elder Affairs, 4040 Esplanade Way, Tallahassee, Florida

Participants

Samira Beckwith, Florida Hospices and Palliative Care, Inc. (FHPC)

Richard Freiberg, D.O.M., D.Ac., Dipl.Ac., Florida State Oriental Medical Association
(FSOMA)

Debra Gressel, Florida Association of Homes for the Aging (FAHA)

Julia Herndon, Florida Association of Insurance and Financial Advisors (FAIFA)

George Mayzell, M.D., Florida Association of Health Maintenance Organization (FAHMO)

Koko Okano, Florida Health Care Association

Marshall Seiden, Florida Association of Homes for the Aging (FAHA)

Dr. JoAnne Bujnoski, Florida Osteopathic Medical Association (FOMA)

Staff Support - Kathi Chisolm, DOEA

Reimbursement Issues

- a) Non-covered Items;
- b) Complimentary/Alternative Medicine;
- c) R.U.G.s Group;
- d) Private Pay-Impoverishment;
- e) Setting/Place of Service--i.e., Home, Hospice, Long-Term Care;
- f) Family Care/Support--caregiver has to leave job to care for relative--impoverishment;
- g) Non-Economic Incentives;
- h) Add-on component to Medicaid end of life care;
- i) Mutually exclusive program coordination;
- j) Link/tie-in hospice/HCFAs and private insurance (HMOs, etc.);
- k) Funding private/public education efforts; and
- l) Insurance payment systems and limits.

NOTE: Review past recommendations of the Panel for the Study of End-of-Life Care.

Incentive Issues

- a) Credit for hospice relationship (towards Gold Seal);
- b) Continuum of Care credit;
- c) CMEs/CEUs;
- d) Publicize and promote past recommendations; and
- e) Education public (Reimbursement and Incentives).

STANDARDS TASK FORCE MEETING SUMMARY

Monday, August 28, 2000 from 1:30 p.m. to 2:45 p.m.
Room 235F, Department of Elder Affairs, 4040 Esplanade Way, Tallahassee, Florida

Participants

Susan Acker, Agency for Health Care Administration (AHCA)
Bill Allen, J.D., M. Div., University of Florida, Bioethics, Law and the Humanities Program
Cathy Emmett, ARNP, Florida Nurses Association (FNA)
Henry Pearson, Florida Assisted Living Association (FALA)
Alvin E. Smith, M.D., Florida Medical Association (FMA)
Peg Terbeek, Florida Life Care Residents Association (FLiCRA)
Freida B. Travis, Department of Health (DOH)
Howard Tuch, M.D., Florida Health Care Association (FHCA)

Staff Support – Beverly Friedberg, DOEA

Standards Issues

- a) Pain management and advance directives - review of other state or countries models of care - including Oregon, Holland, Belgium, Switzerland;
- b) American Medical Association and Hospice has set standards of care;
- c) Legislative issues - gaps and inferences such as “may” - group will develop a list of issues to present to Linda Macdonald;
- d) Collect and review existing research material;
- e) Environmental standards such as assisted living facility (ALF) licensing issues, quality of care, level of care as allowed by rules;
- f) Standards to allow care in the community such as respite;
- g) Look at models to deduce care issues;
- h) Cultural issues - how do they conflict with standards or rules?;
- i) Training people to be better surrogate decision makers;
- j) Active patient/family involvement;
- k) Access for care in rural areas - physical isolation from care;
- l) Education for palliative care
- m) Should palliative care be a specialty? What standards apply?
- n) 156 credit hours required in medical school - so little time - so many training issues;
- o) Standards versus implementation;
- p) Nursing shortage;
- q) Liability insurance; and
- r) Utilization of spiritual care - how to get churches involved?

END-OF-LIFE CARE WORKGROUP MEETING SUMMARY

Monday, October 16, 2000

**Room 225F, Department of Elder Affairs, 4040 Esplanade Way,
Tallahassee, Florida 32399-7000**

Workgroup Members in Attendance

Samira Beckwith, Florida Hospices and Palliative Care, Inc. (FHPC)
Dr. JoAnne Bujnoski, Florida Osteopathic Medical Association (FOMA)
Cathy Emmett, ARNP, Florida Nurses Association (FNA)
Richard Freiberg, D.O.M., D.Ac., Dipl.Ac., Florida State Oriental Medical Association
(FSOMA)
Pat Hall for Susan Acker, Agency for Health Care Administration (AHCA)
Julia Herndon, Florida Association of Insurance and Financial Advisors (FAIFA)
Marshall Kelley, Department of Elder Affairs, **Facilitator**
Linda Macdonald, Department of Elder Affairs (DOEA)
Jim Powers (FPA) for Peggy Ann Zaenger, Florida Pharmacy Association (FPA)
Howard Tuch, M.D., Florida Health Care Association (FHCA)
Henry Pearson, Florida Assisted Living Association (FALA)
Marshall Seiden, Florida Association of Homes for the Aging (FAHA)
Peg Terbeek, Florida Life Care Residents Association (FLiCRA)
Freida B. Travis, Department of Health (DOH)
Susan V. White, PhD, RN, Florida Hospital Association (FHA)
Sharon Zill, PhD, RN, for George Mayzell, M.D., Florida Association of Health Maintenance
Organization (FAHMO)

Workgroup Members Absent

Susan Acker, Agency for Health Care Administration
Representative Heather Fiorentino, Florida House of Representatives
George Mayzell, M.D., Florida Association of Health Maintenance Organization (FAHMO)
Alvin E. Smith, M.D., Florida Medical Association (FMA)
Peggy Ann Zaenger, Florida Pharmacy Association (FPA)
Senator Ron Klein, Florida Senate

Observers in Attendance

Bill Allen, J.D., M. Div., Associate Professor, University of Florida, Bioethics, Law and the
Humanities Program; and the Florida Bioethics Network
Wanda Carter, Senior Legislative Analyst, Senate Health, Aging, Long-Term Care Committee
Debra Gressel, Florida Association of Homes for the Aging
Tom McMullen, Department of Elder Affairs
Koko Okano, Florida Health Care Association
Jessica Swanson, Department of Health

Support Staff in Attendance:

Kathi Chisolm, Beverly Friedberg, Mary Hodges, and Veronica Johnson, DOEA

Call to Order

Marshall Kelley, Director of Statewide Community Based Services in the Department of Elder
Affairs, called the meeting to order at 10:00 a.m. Mr. Kelley welcomed members, reviewed the

meeting agenda and extended apologies for the cancellation of the September 22, 2000 End-of-Life Care Workgroup meeting due to Tropical Storm Helena.

Mr. Kelley asked that each workgroup member introduce himself or herself. After the introductions, Mr. Kelley reviewed the contents of the workgroup member notebooks and distributed the August 28, 2000, meeting summary. The August 28 meeting summary was approved and adopted by the workgroup. Mr. Kelley advised the workgroup the meeting summary, attendance and biographies would be part of the final report.

Linda Macdonald advised the workgroup about reference materials available to them on a back table. The reference materials are:

- Law and Ethics at the End of Life, Florida Bioethics Network Conference brochure;
- Chapter 2000-295, Committee Substitute for Senate Bill No. 1890;
- Annals of Long-Term Care, Volume 8, Number 7, July 2000 article "Best Practices in the Care of the Dying", James Hallenbeck, M.D.;
- Rand Health Abstract, "Quality Improvements in End-of-Life Care: Insights from Two Collaborative, Lynn J. Schall MW, Milne C. Nolan KM, Kabcenell A. The Joint Commission Journal on Quality Improvement, Vol. 26, No. 5, 2000, pp. 254-267;
- Journal of Gerontological Nursing, "Nursing Care at End-of-Life", Virginia P. Tilden, DNS, RN, FAAN;
- United States General Accounting Office Testimony, Medicare, September 18, 2000;
- Associated Press, "Drop in Hospice Days Concerns Lawmakers";
- The Wall Street Journal, "Medicare Head Tackles Criticism on Hospice Care", September 18, 2000;
- New York Times, article on Medicare and hospice care, September 18, 2000;
- Last Acts web site information, <http://www.lastacts.org>;
- Caring for the Ages, August 2000, "Caring for the Dying: A Growing Concern", Duncan S. MacLean, MD, CMD;
- Last Acts, "Precepts of Palliative Care", developed by the Task Force on Palliative Care, December 1997;
- "Medicare Beneficiaries' Costs and Use of Care in the Last Year of Life", Final Report, May 1, 2000, submitted to Medicare Payment Advisory Commission;
- Department of Health and Human Services, Health Care Financing Administration, letter to Medicare Hospice providers;
- Community-State Partnerships to Improve End-of-Life Care, Policy Update from the Community-State Partners: Summer 2000;
- Florida Focus on End-of-Life Issues, Volume I, Number 1, July 31, 2000 and
- Nurses Need Better Grasp of DNR Orders – description of study described in the Journal of Nursing Scholarship, September 22, 2000.

Mr. Kelley introduced Mr. Bill Allen to provide a brief summary of end-of-life care issues he had compiled in a paper on the significance of confidentiality and Florida Statute 765 related to withholding treatment.

Bill Allen, J.D., M. Div., Associate Professor, University of Florida, Bioethics, Law and the Humanities Program; and the Florida Bioethics Network presented an overview of the Background Information paper he had compiled and distributed to the workgroup.

Issues raised by Mr. Allen's presentation included:

- Significance of "Right to privacy"
- Use of the terms "may"/"must" in the Do Not Resuscitate Order (DNRO)
- Transferability of the DNRO from one facility to another
- DNRO refers to cardio pulmonary resuscitation (CPR) only
- Use of the term "order" in the Do Not Resuscitate Order (DNRO)
- Options for withholding/withdrawal of life sustaining treatment, Chapter 765, F.S.
- Suggestion to call it a "refusal to resuscitation" form so that a physician's order could then be written at each institution based on the consumers refusal for resuscitation
- Discussion of the terms "terminal condition" and "end stage condition" and implications for the differences
- "End stage condition" includes "reasonable medical certainty" versus "terminal" which includes "reasonable medical probability"
- Discussion of the definition of futility and treatment implications

Mr. Kelley thanked Mr. Allen for his presentation. He then introduced Samira Beckwith and advised that she would provide information about a grant she is working on to deal with end-of-life issues for children.

Samira Beckwith, President of the Florida Hospices and Palliative Care, Inc. presented an overview of the grant, Program for All Inclusive Care for Children. Please see the one page grant summary included in the End-of-Life Care Workgroup notebook under tab 5. The Health Care Finance Administration has approved five demonstration projects to improve the quality of service provided to children with life threatening conditions, Florida being one of the grant recipients. The grant partners consist of the Florida Medicaid program, the Department of Health, Division of Children's Medical Services (Title V Program), and Florida hospices. The grant will identify barriers to end-of-life care and choice between palliative care and life prolonging care. The grant is also designed to develop a model program for end-of-life care for children. Ms. Beckwith advocated for the workgroup giving consideration to children's issues.

Mr. Kelley thanked Ms. Beckwith for her work and presentation. Mr. Kelley then asked the workgroup to bring to the Department any emerging issues. Mr. Kelley presented the draft work plan to accomplish writing the workgroups mandated report to the legislature. He asked each task force to select a facilitator and to work with DOEA staff to write the summary. Mr. Kelley asked for any suggestions on how the workgroup members can accomplish the workgroup's objectives. **Mr. Kelley reminded the workgroup that the draft task force reports are due November 30, 2000 to DOEA.**

The draft work plans for the Standard Task Force and the Reimbursement Task Force were distributed to workgroup members. A timeline for completion of the objectives was also distributed. The draft work plans are attached to this meeting summary.

Mr. Kelley then asked the workgroup to breakout into the task forces. The Standard Task Force and the Reimbursement Task Force then split into separate groups and agreed to reconvene into the larger workgroup for a working lunch. During the working lunch, future meeting dates were discussed.

Several dates were discussed with a the following agreement by workgroup members:

- ✓ **November 13, 2000**, from 10:00 a.m. to 5:00 p.m. will be held in Tallahassee;
- ✓ **November 14, 2000**, from 8:30 a.m. to 5:00 p.m. will be held in Tallahassee; and
- ✓ **November 27, 2000**, from 10:00 a.m. to 3:00 p.m. was tentatively scheduled to be held in Tallahassee if the workgroup decides another meeting is necessary to complete the mandated legislative report.

The final report was discussed. Marshall Seiden asked Mr. Kelley whether the report is a product of the Department of Elder Affairs or a product of the workgroup. Mr. Kelley stated the law provides for the report to be a product of the workgroup. Paragraph 4 of section 16 of Chapter 295-2000, Laws of Florida states:

The workgroup shall submit a report of its findings and recommendations to the Governor, the President of the Senate, and the Speaker of the House of Representatives by December 31, 2000.

The working lunch concluded with Ms. Beckwith asking for a representative from the Department of Insurance to meet with the Reimbursement Task Force. It was agreed the Department would locate someone to speak to the group at a future End-of-Life Care Workgroup meeting.

From 1:00 p.m. to 2:15 p.m. the Standards and Reimbursement Task Forces reconvened. The workgroup reconvened at 2:15 p.m. Mr. Kelley thanked the members for their work on these important issues and asked each task force to present their findings.

Samira Beck, President of the Florida Hospices and Palliative Care, Inc. presented the findings of the Reimbursement Task Force. The issues discussed were:

- ✓ To request that a representative from the Department of Insurance speak to them. Suggested a possible contact with the Department of Insurance;
- ✓ To review the need for possible legislative funding for services in rural and underserved areas;
- ✓ To provide adequate funding for public and professional end-of-life care education with specific initiatives for rural and other underserved populations as provided in Section 765.102(5), Florida Statutes;
- ✓ To develop a bill whereby healthcare providers will receive Medicaid supplemental payments when providing end-of-life services (similar to the Medicaid reimbursement plan for HIV and the medically fragile);

- ✓ To bring the state into compliance with federal law such that patients are not excluded from programs that they are dually eligible for unduplicated services whether it be Medicare, Medicaid, etc.;
- ✓ To provide recognition and reimbursement of complimentary or alternative medicine in end of life care. To recommend that all payers be reimbursed for complimentary or alternative therapies; and
- ✓ To recommend end-of-life care continuing education requirements for acupuncturist.

Some issues discussed by the workgroup after Ms. Beckwith’s presentation included:

- Need for data about the current costs associated with end-of-life care;
- Anecdotal information about massive surgeries in the last few days of life;
- The Long Term Care Task Force on Availability and Affordability of Care; and
- Seriousness of the cost of insurance and impact on seniors who must pay higher rates of care because of the cost of insurance to care providers.

Mr. Kelley thanked Ms. Beckwith for her report and asked the Standards Task Force to present the findings of their break out meeting.

Pat Hall, ACHA representative for Dr. Acker presented the findings of the Standards Task Force. The Standards Task Force decided to focus on two main areas regarding standard of end-of-life care: 1) palliative care and 2) advance directives. The task force developed the matrix below to assist members in conceptualizing palliative and advance directive standards.

	Acute Care Settings	Nursing Home Settings	Assisted Living Settings	Home and Community Based Settings
Clinical Standards of care				
Education Standards - Professional - Consumer				
Cultural Competency				
Research				
Access				

The task force intends to make recommendations that will address the full continuum of health care settings. The task force members agreed to review and modify existing palliative care standards and current advance directives. The task force also intends to recommend a few steps, which may translate into legislative initiatives.

The Standards Task Force further agreed that Dr. Tuch would take lead on the palliative care topic and Bill Allen would take lead on the advance directives topic. Dr. Tuch and Bill Allen will each prepare a draft paper outlining recommendations on the standard of care that will be sent to all workgroup members for review. Dr. Tuch stated he would send his notes on the matrix to DOEA to disseminate to the workgroup members.

Mr. Kelley reminded the workgroup that any materials produced for this workgroup would be sent to all workgroup members. Mr. Kelley provided a summary of the meeting and thanked the workgroup members for their participation and work to help write the report. The meeting was adjourned at 3:00 p.m.

REIMBURSEMENT TASK FORCE MEETING SUMMARY

Monday, October 16, 2000 from 10:30 a.m. to 2:45 p.m.

Room 235M, Department of Elder Affairs, 4040 Esplanade Way, Tallahassee, Florida

Participants

Samira Beckwith, Florida Hospices and Palliative Care, Inc. (FHPC)

Dr. JoAnne Bujnoski, Florida Osteopathic Medical Association (FOMA)

Richard Freiberg, D.O.M., D.Ac., Dipl.Ac., Florida State Oriental Medical Association (FSOMA)

Julia Herndon, Florida Association of Insurance and Financial Advisors (FAIFA), Member

Marshall Seiden, Florida Association of Homes for the Aging (FAHA)

Sharon Zill, PhD, RN, for George Mayzell, M.D., Fla Ass. of Health Maintenance Organization (FAHMO)

Debra Gressel, Florida Association of Homes for the Aging (FAHA)

Koko Okano, Florida Health Care Association (FHCA)

The Reimbursement Task Force designated Samira Beckwith to be their facilitator. She did remind the task force that she would not be able to attend the next scheduled meeting on November 13, 2000. Ms. Beckwith asked the task force prioritize the list of issues from the August 28, 2000 meeting into five main areas of interest.

Reimbursement Issues

The workgroup discussed the following topics:

Prioritizing issues from the August 28, 2000 Reimbursement Task Force meeting

- Complimentary or alternative medicine;
- Palliative care education and inability to substitute this type of education for the currently required AIDS continuing education requirements;
- Insurance reimbursement rates;
- High attorney settlement fees;
- Nursing homes closing;
- Insurance and long-term care policy information available through the DOI; and
- Dr. Zill and Ms. Herndon agreed to research insurance issues and bring some information back to the workgroup at the next meeting on November 13, 2000.

Reimbursement Recommendations

The workgroup decided to focus on the following list of five prioritized goals:

1. To provide adequate funding for public and professional education with specific initiatives for rural and other underserved populations as provided in Section 765.102(5), Florida Statutes;
2. To develop a bill whereby healthcare providers will receive Medicaid supplemental payments when providing end-of-life care services (similar to the Medicaid reimbursement plan for HIV and the medically fragile);
3. To bring the state into compliance with federal law such that patients are not excluded from programs that they are dually eligible for unduplicated services whether it be Medicare, Medicaid, etc.;

4. To provide recognition and reimbursement of complimentary medicine in end of life care. Require all payers to reimburse for complimentary therapies; and
5. To recommend continuing education requirements for end-of-life care continuing education for acupuncturist.

The task force also decided to invite Edwin Bodo, Florida Health Care Association and Laurie Goldman, Senior Attorney from the Department of Insurance to attend the next Reimbursement Task Force meeting.

STANDARDS TASK FORCE MEETING SUMMARY

Monday, October 16, 2000 from 10:30 a.m. to 2:45 p.m.
Room 225F, Department of Elder Affairs, 4040 Esplanade Way, Tallahassee, Florida

Participants

Pat Hall for Susan Acker, Agency for Health Care Administration (AHCA)
Bill Allen, J.D., M. Div., University of Florida, Bioethics, Law and the Humanities Program
Wanda Carter, Senior Legislative Analyst, Senate Health, Aging, Long-Term Care Committee
Cathy Emmett, ARNP, Florida Nurses Association (FNA)
Linda Macdonald, MS, Department of Elder Affairs (DOEA)
Jim Powers for Peggy Ann Zaenger, Florida Pharmacy Association (FPA)
Henry Pearson, Florida Assisted Living Association (FALA)
Peg Terbeek, Florida Life Care Residents Association (FLiCRA)
Freida B. Travis, Department of Health (DOH)
Howard Tuch, M.D., Florida Health Care Association (FHCA)
Susie White, PhD, RN, Florida Hospital Association (FHA)

The Standards Task Force designated Susan Acker to be their facilitator. Ms. Pat Hall acting on behalf of Ms. Acker asked the group to prioritize the list of issues from the 8/29/00.

Standards Issues

The workgroup discussed the following topics:

- Prioritizing issues from the August 28, 2000 Standards Task Force meeting;
- Patient's Bill of Rights, legal ramifications in regard to right access, pain management;
- Endorsement or modification of existing resources such as the American Medical Association Standards to help write the Standards Task Force Report;
- Three documents were distributed:
 - * Position statement by the American Geriatrics Society Ethics Committee on "The Care of Dying Patients";
 - * American Medical Association, "Elements of Quality Care for the Patients in the Last Phase of Life" and;
 - * The Network News, Winter 1997 edition newsletter on "Medicine's Response to Supreme Court's Decision and the Institute of Medicine Recommendations for Improving the Care of the Dying"
- Curriculum/Education issues for professionals and public;
- DNRO language and possibility of recommending changes in statute; and
- Cultural competency.

Standards Recommendations

The workgroup decided to focus on two main areas of concern: 1) palliative care and 2) advance directives. The task force agreed that Dr. Tuch would take lead on the palliative care topic and Bill Allen would take lead on the advance directives topic. Dr. Tuch and Bill Allen will each prepare a draft paper outlining recommendations on the standard of care that will be sent to all workgroup members for review. Dr. Tuch stated he would send his notes on the matrix to Linda Macdonald to disseminate to the workgroup. Ms. Hall also presented the information matrix developed by Dr. White, which established the framework for writing the reports.

END-OF-LIFE CARE WORKGROUP MEETING SUMMARY

Monday, November 13, 2000
Room 225F, Department of Elder Affairs, 4040 Esplanade Way,
Tallahassee, Florida 32399-7000

Workgroup Members in Attendance

Susan Acker, Agency for Health Care Administration (AHCA)
Elaine Bartelt for Samira Beckwith, Florida Hospices and Palliative Care, Inc. (FHPC)
Dr. JoAnne Bujnoski, Florida Osteopathic Medical Association (FOMA)
Marie Cowart for Cathy Emmett, ARNP, Florida Nurses Association (FNA)
Richard Freiberg, D.O.M., D.Ac., Dipl.Ac., Florida State Oriental Medical Association
(FSOMA)

Representative Heather Fiorentino, Florida House of Representatives
Carol Gromley, for Susan White, M.D., Florida Hospital Association (FHA)
Marshall Kelley, Department of Elder Affairs, Facilitator
Senator Ron Klein, Florida Senate
Linda Macdonald, Department of Elder Affairs (DOEA)
Henry Pearson, Florida Assisted Living Association (FALA)
Marshall Seiden, Florida Association of Homes for the Aging (FAHA)
Alvin E. Smith, M.D., Florida Medical Association (FMA)
Peg Terbeek, Florida Life Care Residents Association (FLiCRA)
Freida B. Travis, Department of Health (DOH)
Howard Tuch, M.D., Florida Health Care Association (FHCA)
Sharon Zill, PhD, RN, for George Mayzell, M.D., Florida Association of Health Maintenance
Organization (FAHMO)

Observers in Attendance

Bill Allen, J.D., M. Div., Associate Professor, University of Florida, Bioethics, Law and the
Humanities Program; and the Florida Bioethics Network
Cam Fentriss, Attorney at Law
Debra Gressel, Florida Association of Homes for the Aging
Marty A. Ratliff, RN, BSN, OCN, Project GRACE
Bennett Napier, Florida Life Care Residents Association (FLCRA)
Koko Okano, Florida Health Care Association

Workgroup Members Absent

Samira Beckwith, Florida Hospices and Palliative Care, Inc. (FHPC)
Cathy Emmett, ARNP, Florida Nurses Association (FNA)
George Mayzell, M.D., Florida Association of Health Maintenance Organization (FAHMO)
Herb Morgan, Florida Association of Insurance and Financial Advisors (FAIFA)
Susan White, M.D., Florida Hospital Association (FHA)
Peggy Ann Zaenger, Florida Pharmacy Association (FPA)

Support Staff in Attendance:

Beverly Friedberg, Mary Hodges, and Veronica Johnson

Call to Order

Marshall Kelley, called the meeting to order at 10:00 a.m. on November 13th. Mr. Kelley welcomed members and asked member alternates to introduce himself or herself to the workgroup. After the introductions, Mr. Kelley reviewed the meeting agenda, the workgroup's mission, and provided an overview of the prior meetings. He reminded the workgroup that another meeting is noticed for November 27, 2000 and the decision as to whether it was needed would be made during the course of the next two days. Mr. Kelley reviewed the timelines for completing the draft report. He suggested that because of the complexities of the issues, it may be helpful for the Standards and the Reimbursement Task Forces to start with the highest priorities.

Mr. Kelley indicated even though the final report is due December 31, 2000, the workgroup may need to reconvene during legislative session to assist legislators with information requests on the end-of-life issues. The minutes from the October 16, 2000 meeting were approved and adopted by the workgroup with the correction of the name of the Department for Freida Travis.

Mr. Kelley discussed Robert Wood Johnson Foundation report entitled "Pioneer Programs in Palliative Care: Nine Case Studies". He asked that all members review and provide comments on the report tomorrow. Mr. Kelley especially hoped to receive the comments from those organizations closely involved with hospitals such as the Florida Hospital Association. Linda Macdonald introduced the Department of Insurance (DOI) representatives, Laura Goldman and Frank Dino to the members. DOI representatives were present to meet with the Reimbursement Task Force during the break out session. Mr. Kelley welcomed the representatives from DOI and indicated Erwin Bodo, Ph.D. with Florida Association of Homes for the Aging would also be joining the Reimbursement Task Force later. He reminded the workgroup that other expertise will be made available upon request.

Mr. Kelley noted that in the 10/16 meeting summary the Reimbursement Task Force had listed the following issue: "To bring the state into compliance with federal law such that patients are not excluded from programs that they are dually eligible for unduplicated services whether it be Medicare, Medicaid, etc." Mr. Kelley stated that the Florida's Medicaid program does exclude individuals from receiving hospice services while residing in an assisted living facility. Mr. Kelley requested that this meeting summary reflect that the State of Florida is in compliance with this issue.

Linda Macdonald reviewed the handouts including:

- Robert Wood Johnson Foundation report entitled "Pioneer Programs in Palliative Care: Nine Case Studies"
- AMDA Model Care Facility
- AAPM Clinical Library, Publications and Products, "The Use of Opioids for the Treatment of Chronic Pain"
- AAPM Clinical Library, Publications and Products, "Basic Principles of Ethics for the Practice of Pain Medicine"
- AAPM Clinical Library, Publications and Products, "Consent for Chronic Opioid Therapy"

- Comprehensive Accreditation Manual for Hospitals: The Official Handbook (CAMH): Patient Rights and Organization Ethics chapter
- American Geriatrics Society (AGS) Position Statement "The Care of the Dying Patients"
- Principles for Care of Patients at the End of Life: An Emerging Consensus Among the Specialties of Medicine by Christine K. Cassel and Kathleen M. Foley, December 1999"
- The Management of Chronic Pain in Older Persons, AGS Panel on Chronic Pain in Older Persons, Clinical Practice Guidelines
- Florida Department of Insurance, Options for Lifelong Care booklet
- Department of Elder Affairs, Long-Term Care Insurance Self Assessment Guide produced by the Service Health Insurance Needs of Elders (SHINE) Program
- National Association of Insurance Commissioners, A Shopper's Guide to Long-Term Care Insurance
- Advance Directive Forms from each of the fifty states
- Project GRACE Advance Care Planning documents
- The News Network, Covering hospice care, palliative care, and end-of-life care issues, Volume 9, Number 91 dated November 10, 2000
- Draft Work Plans for the Final Workgroup Report, Reimbursement Task Force and Standards Task Force

Mr. Kelley also advised the members of paper entitled "Standards for Advance Care Planning and Implementation" prepared by Bill Allen and the paper "Standards for Palliative Care" prepared by Dr. Howard Tuch. These papers outlined draft recommendations from the Standards Task Force meeting on 10/16. Mr. Kelley thanked them for all their work in preparing these documents. The two documents were distributed to the workgroup members.

Mr. Kelley indicated he would check with the Reimbursement and Standards Task Forces later that day to determine whether they wanted to reconvene in the larger group or continue with the break out task forces until 5:00 p.m. Mr. Kelley then asked that the task forces reconvene to continue working on their objectives. The members decided that they would have lunch on their own on November 13th.

The Workgroup reconvened at 3:40 p.m. on November 13th. Linda Macdonald thanked the members for their work on these important issues and asked each task force to present their findings for discussion.

Marshall Seiden acted on behalf of Samira Beckwith as the spokesperson for the Reimbursement Task Force. Mr. Seiden reported that the task force revised the previous list of issues. He stated that the representatives from DOI were very helpful and provided valuable information to the task force. He stated that DOI reported growth of long-term care insurance products. Also, continued concerns were reported about the cost of long-term care insurance policies. Mr. Seiden stated that the task force found Dr. Erwin Bodo reported on Florida Medicaid issues to be extremely helpful.

Mr. Seiden reviewed the Reimbursement Task Force revisions to the 10/16 recommendations. The task force revised the 1st and 4th recommendations, and deleted the 3rd and 5th recommendations. The 2nd recommendation was pending consideration for change by the

Reimbursement Task Force. Find below the revisions to the 1st and 4th recommendation made on 10/16:

1. Provide adequate public funding for the public at large and health care professionals for education on end of life care, with specific initiatives for rural and other under served populations as provided in section 765.102 (5), F.S.
4. Recognize health care professionals licensed under chapters 457, 458, 459, 460, and 464, F.S., providing end of life care services, and reimburse them under the state Medicaid methodologies and insurance plans, in accordance with sections 627 and 641, F.S.

A question was raised about whether the workgroup is supposed to recommend specific legislative language, propose a bill, or just state recommendations. Mr. Kelley reviewed the End-of-Life Care Workgroup's objectives as stated in Chapter 2000-295, Laws of Florida, which state that the workgroup shall:

- (a) Examine reimbursement methodologies for end-of-life care;
- (b) Identify end-of-life care standards that will enable all health care providers along the health-care continuum to participate in an excellent system of delivering end-of-life care; and
- (c) Develop recommendations for incentives for appropriate end-of-life care.

Mr. Kelley stated it was up to the members to decide whether they wanted to recommend specific changes to Florida Statute or not. Members indicated that if possible, the workgroup's report should include recommendations for specific changes to Florida Statutes.

The workgroup went on to discuss the following issues:

- Consideration of recommending to the Florida Legislature that a pilot project be funded such as the Balm of Gilead Center located in Alabama;
- Greater focus on end-of-life care services above and beyond what is currently being provided by Medicaid, Medicare, or other insurance in needed;
- Differentiation between hospice services and nursing home services;
- End-of-life care services need to include the extra time doctors need to spend with patients and families;
- The wording "allow to bill for" should be used rather than the use of the word "recognition" in number 4 listed above;
- Florida's current Medicaid spending is approximately \$2,000 per person compared to approximately \$8,000 per person in New York;
- Need to recognize the potential fiscal impact of any recommendations to the Legislature and likelihood of obtaining funding;
- Concerns about "alternative" or "complimentary" treatment not being allowed as a billable activity;
- Costs associated with "alternative" or "complimentary" treatment were discussed both in light of cost savings and cost increases;
- Sending a letter to Congress recommending the Hospice benefit be increased from 6 months or 1 year as provided for in Florida; and

- Need to include in-service training substitution of end-of-life care issues for the required HIV and Domestic Violence training for CNAs – this group of individuals was inadvertently left out of statute.

Bill Allen presented a summary of the advance directive standards for the Standards Task Force. The issue paper dated November 8, 2000 entitled “Standards for Advance Care Planning and Implementation” was referenced. Issues raised as part of this discussion include:

- Possible recommendation for a statute change - raising the bar to “substantial uncertainty” or another word such as “significant uncertainty” rather than “any question” in regard to capacity to make a decision;
- Bill Allen agreed to write options for consideration by the workgroup to respond to for tomorrow’s meeting;
- Importance of documentation of verbal consent;
- “Best interest” standard being broadened either by expansion of the definition or through procedural remedies;
- Discussion of changing the definition for “end stage condition” or removal of all three criteria; and
- Reminder of the importance of the potential discrimination of individuals due to socio-economic factors.

Mr. Kelley thanked the members for their hard work on these difficult issues, reminded members that the meeting starts tomorrow at 8:30 a.m., and adjourned the meeting at 5:15 p.m.

END-OF-LIFE CARE WORKGROUP MEETING SUMMARY

Tuesday, November 14, 2000
Room 225F, Department of Elder Affairs, 4040 Esplanade Way,
Tallahassee, Florida 32399-7000

Participants

Susan Acker, Agency for Health Care Administration (AHCA)
Elaine Bartell and Lynne M. Mulder for Samira Beckwith, Florida Hospices and Palliative Care, Inc. (FHPC)
Marie Cowart for Cathy Emmett, ARNP, Florida Nurses Association (FNA)
Richard Freiberg, D.O.M., D.Ac., Dipl.Ac., Florida State Oriental Medical Association
Representative Heather Fiorentino, Florida House of Representatives
Carol Gromley, for Susan White, M.D., Florida Hospital Association (FHA)
Marshall Kelley, Department of Elder Affairs, **Facilitator**
Linda Macdonald, Department of Elder Affairs (DOEA)
Henry Pearson, Florida Assisted Living Association (FALA)
Marshall Seiden, Florida Association of Homes for the Aging (FAHA)
Alvin E. Smith, M.D., Florida Medical Association (FMA)
Peg Terbeek, Florida Life Care Residents Association (FLiCRA)
Freida B. Travis, Department of Health (DOH)
Howard Tuch, M.D., Florida Health Care Association (FHCA) (Telephone conference)
Sharon Zill, PhD, RN, for George Mayzell, M.D., Florida Association of Health Maintenance Organization (FAHMO)

Observers in Attendance

Bill Allen, J.D., M. Div., Associate Professor, University of Florida, Bioethics, Law and the Humanities Program; and the Florida Bioethics Network
Debra Gressel, Florida Association of Homes for the Aging
Marty A. Ratliff, RN, BSN, OCN, Project GRACE
Koko Okano, Florida Health Care Association

Workgroup Members Absent

Samira Beckwith, Florida Hospices and Palliative Care, Inc. (FHPC)
Dr. JoAnne Bujnoski, Florida Osteopathic Medical Association (FOMA)
Cathy Emmett, ARNP, Florida Nurses Association (FNA)
Senator Ron Klein, Florida Senate
George Mayzell, M.D., Florida Association of Health Maintenance Organization (FAHMO)
Herb Morgan, Florida Association of Insurance and Financial Advisors (FAIFA)
Susan White, M.D., Florida Hospital Association
Peggy Ann Zaenger, Florida Pharmacy Association (FPA)

Support Staff in Attendance:

Beverly Friedberg, Mary Hodges, and Veronica Johnson

Call to Order

Marshall Kelley, Director of Statewide Community Based Services in the Department of Elder Affairs, called the meeting to order at 8:30 a.m. on November 14th. Mr. Kelley welcomed members and the workgroup decided to hold the workgroup meeting

November 27, 2000. Mr. Kelley indicated the final report is due December 31, 2000, to the Legislature. He stressed the need for the members to put the issues in writing before the next meeting.

Mr. Kelley then asked the task forces to reconvene and to continue their development of recommendations. Plans were made to have a working lunch because several members would have to leave the meeting before 5:00 p.m. to catch airplane flights. It was determined that the workgroup would reconvene at 10:30 a.m. and to report the task force recommendations.

The Workgroup reconvened at 10:30 a.m. Mr. Kelley welcomed the members back into the large group and requested that the task forces report their recommendations to the full workgroup. Mr. Kelley stated it is important to finalize the issues and start preparation for the final report.

Lynne Mulder acted on behalf of Samira Beckwith as the spokesperson for the Reimbursement Task Force. The issues discussed were:

- Terminally ill definition in Chapter 400 and 765, F.S.;
- One year or less is regarding prognosis not diagnosis;
- Definition of patient in Chapter 400, F.S.;
- Extension of initial certification period to receive hospice services;
- Are the definitions of terminally ill (chapter 400, F.S.) and terminal (chapter 765, F.S.) compatible;
- Discussion of mandating versus recommending reimbursement for complimentary medicine in end-of-life care. Some members stated "alternative" or "complimentary" services would add costs and others stated it would decrease costs. Concern about increasing costs for uninsured people. Concern that adding alternative" or "complimentary" medicine would significantly impact on the cost of the health care system. Concerns that hospice would be out of business due to cost factors if "alternative" or "complimentary" care were mandated. Mandating "alternative" or "complimentary" care would shift funds from patient's out-of-pocket expenses to taxpayers and increase the costs of long-term care insurance;
- Frequency of visits for care such as chiropractic care increases, thereby raising costs;
- Access to "alternative" or "complimentary" care or non-traditional care, with particular attention to pain management. AGA study of pain management shows alternate treatments as being useful;
- Concern about discrimination against licensed acupuncturist by insurance companies;
- Client choice and having options was stressed;
- Important to know what "alternative" or "complimentary" care are currently available because there is some coverage for these treatments already in place;
- Statement that Medicaid pays for acupuncture for AIDS patients in certain circumstances;
- Research by the American Geriatrics Society points to value of "alternative" or "complimentary" care;

- Focus on what could be considered “alternative” or “complimentary” care for pain management as something the workgroup could agree on;
- Concern about blocked access for hospice services in nursing homes;
- Issue of unadopted codes for billing for “alternative” or “complimentary” care; and
- AHCA can provide any available data for research needs regarding “alternative” or “complimentary” care.

It was agreed that Dr. Freiberg would write the pros for this discussion while Sharon Zill would develop the cons.

Linda Macdonald noted that Dr. Tuch was available by telephone conferencing to discuss his paper on the recommendations for palliative care standards. First, Bill Allen reviewed the recommendations regarding advance directives standards prepared by the Standards Task Force.

The Standards Task Force drafted the following two alternatives for consideration by the Workgroup:

Alternative One

Substituted judgment must be the preferred standard of decision-making used by health surrogates, durable powers of attorney for health care, and proxy decision-makers, but when there is no indication what the principal would have chosen, proposed or currently in place treatments may be withheld or withdrawn by the surrogate, D.P.A.H., or proxy’s decision under a best interest standard.

The threshold alternative criteria required to be certified in order to withhold or withdraw life-sustaining treatment should be omitted from F.S. 765.

Alternative Two

The threshold alternative criteria required to be certified in order to withhold or withdraw life-sustaining treatment should be omitted from F.S. 765.

If these criteria are not omitted, “end stage condition” definition should be changed to read as follows:

765.01(4): End stage condition means a condition that is caused by injury, disease, or illness which has resulted in severe and permanent deterioration, indicated by incapacity and significant physical dependency, and for which the patient, resident, or authorized representative would deem curative treatment to be more of a burden than a benefit.

Issues Discussed

- Expands substituted judgment;
- How will “best interest” standard be determined?;
- Cultural differences need to be considered;
- Bill Allen stated there are definitions for “best interest”;

Legislative changes workgroup agreed on were:

- Omit the three conditions in Chapter 765, F.S.,
- Omit as threshold criteria – use best interest, and
- If these are not adopted, then the fall back position is Alternative Number Two.

Marshall Kelley thanked Bill Allen for his work on these issues. The workgroup agreed to take a 10-minute break and reconvened at noon. Linda Macdonald connected Dr. Tuch by conference call. Dr. Tuch reviewed the document he had prepared; "Standards for Palliative Care" dated 11-10-00 (see attached).

Issues discussed:

1. Definition of Palliative Care

- There are other definitions for palliative care, and
- Integration earlier in the process of death.

2. Access

- Concerns about unfunded mandates;
- Dying patients should have access to palliative care;
- Like to stimulate communities to contribute to the discussion;
- Use of word "dying" instead of "terminally ill";
- Promoting palliative care in all aspects of health care;
- The word "dying" not consistent with the words "incurable, progressive illness" in the proposed definition of Palliative Care;
- Need to stay on message (as outlined in Chapter 2000-295, Laws of Florida) that workgroup's objective relates to end-of-life care issues;
- Word "terminal" okay but with caution that it is in practical terms used to mean the last few days or weeks of life; and
- Dr. Tuch indicated he would work with the wording some more.

3. Quality

- Definition adopted from American Medical Association,
- Susan Acker will develop a matrix of Quality standards that already exist the Florida Statutes to cross reference the list presented by Dr. Tuch and the Standards Task Force, and
- Patient's moral framework also must be considered when treating terminally ill.

4. Research

- Need to stimulate new research on Palliative Care and end-of-life care;
- Need to fund demonstration projects focused on either minorities or a rural area;
- Suggestion made that we ask for a study not a demonstration project;
- Suggestion to build on existing data;
- Robert Wood Johnson Foundation report entitled "Pioneers Programs in Palliative Care: Nine Case Studies" was referenced as examples of existing demonstration projects with data available to either model or to combine into a new demonstration project. The demonstration project should identify people who are falling through the cracks;
- Costs for funding a study or project an issue;
- Costs could be absorbed by using existing resources differently – budget neutral concept;
- Care needs to be taken not to use cost savings as an argument;

- Suggestion to use other resources such as grant funds for the study or project;
- DOH has criteria to develop and implement a demonstration project, however, DOH does not have any funds for such a project.

5. Education

- Idea of a “certification program” or “training program” for surrogate decision makers. The term “certification program” is problematic because someone could infer that that you must go through training to become a health care surrogate.
- Suggestion to use “Trained Surrogate”;
- Possible could create a new market for companies providing training;
- Possible develop a volunteer program modeled after DOEA’s SHINE as a mechanism to provide on-going health care surrogate training. Utilizing existing agency resources/expertise available to create good products such as videos;
- Suggestion to contact current continuing education (CE) providers to determine the potential market for end-of-life care training;
- Recommend a Fellowship Program for end-of-life care specialty for Colleges of Medicine;
- Existing program in Canada – could be used as a model – including curriculum; and
- Concerns were raised about the cost of a Fellowship program and resistance to the idea.

Mr. Kelley thanked the members and advised them about the meeting on November 27, 2000 from 10:00 a.m. to 3:00 p.m. This meeting will allow the members the opportunity to vote on the priorities and recommendations for the final report. A meet-me conference call number will be established for those who cannot be physically present for the meeting in Tallahassee on November 27th. There was discussion about getting the meeting summary and the draft recommendations prepared quickly to get to the participants before the Thanksgiving holiday. Susan Acker advised the matrix she will be working on will be ready for the final report but not before the next meeting. The meeting was adjourned at 1:30 p.m.

DRAFT END-OF-LIFE CARE WORKGROUP MEETING SUMMARY

Monday, November 27, 2000
Room 225F, Department of Elder Affairs, 4040 Esplanade Way,
Tallahassee, Florida 32399-7000

Participants

Susan Acker, Agency for Health Care Administration
Samira Beckwith, Florida Hospices and Palliative Care, Inc. (FHPC) (by telephone conference)
Dr. JoAnne Bujnoski, Florida Osteopathic Medical Association (FOMA)
Cathy Emmett, ARNP, Florida Nurses Association (FNA) (by telephone conference)
Richard Freiberg, D.O.M., D.Ac., Dipl.Ac., Florida State Oriental Medical Association
(FSOMA) (On-site and telephone conference)
Julia Herndon, Florida Association of Insurance and Financial Advisors (FAIFA)
Marshall Kelley, Department of Elder Affairs, **Facilitator**
Linda Macdonald, Department of Elder Affairs (DOEA)
Henry Pearson, Florida Assisted Living Association (FALA)
Jim Powers for Peggy Ann Zaenger, Florida Pharmacy Association (FPA)
Marshall Seiden, Florida Association of Homes for the Aging (FAHA)
Alvin E. Smith, M.D., Florida Medical Association (FMA)
Freida B. Travis, Department of Health (DOH)
Howard Tuch, M.D., Florida Health Care Association (FHCA)
Susan White, M.D., Florida Hospital Association

Observers in Attendance

Bill Allen, J.D., M. Div., Associate Professor, University of Florida, Bioethics, Law and the
Humanities Program; and the Florida Bioethics Network
Bill Bell, Florida Hospital Association (FHA)
Debra Gressel, Florida Association of Homes for the Aging (FAHA)
Koko Okano, Florida Health Care Association (FHCA)
Marty A. Ratliff, RN, BSN, OCN, Project GRACE
Jessica Swanson, Department of Health (DOH)
Workgroup Members Absent
Representative Heather Fiorentino, Florida House of Representatives
Senator Ron Klein, Florida Senate
George Mayzell, M.D., Florida Association of Health Maintenance Organization (FAHMO)
Herb Morgan, Florida Association of Insurance and Financial Advisors (FAIFA)
Peg Terbeek, Florida Life Care Residents Association (FLiCRA)
Peggy Ann Zaenger, Florida Pharmacy Association (FPA)

Support Staff in Attendance:

Beverly Friedberg, Mary Hodges, Kathi Chisholm, Ann Wagner, DOEA

Call to Order

Linda Macdonald called the meeting to order at 10:00 a.m. Ms. Macdonald explained that Mr. Kelley would not be able to facilitate the morning meeting because he unexpectedly had been directed to attend a meeting at the Capitol for the Secretary of the Department of Elder Affairs. Mr. Kelley requested that Ms. Macdonald facilitate the meeting in his place. Ms. Macdonald explained to the workgroup that Mr. Kelley did plan to attend the afternoon session. Ms. Macdonald asked that the workgroup members that had joined the meeting by

through the telephone conference to identify themselves. Ms. Samira Beckwith and Cathy Emmett indicated that they had joined the workgroup meeting by telephone conference.

Ms. Macdonald asked that the members review the November 13th and 14th meeting summaries included in the day's meeting materials. Due to the holidays and short turn-around time, the meeting summaries could not be provided to the members any sooner than today. Ms. Macdonald explained that she had e-mailed these meeting summaries to both Ms. Beckwith and Ms. Emmett this morning. The workgroup members were asked to report any corrections to the November 13th and 14th meeting summaries as soon as possible. The workgroup was reminded that the meeting summaries would be included as part of the final report.

Ms. Macdonald reported that the 1st draft recommendations were e-mailed on November 17th to all members. On November 20, a fax copy was sent of the 1st draft recommendations to those members that had difficulty receiving the information by e-mail including:

1. 1st Draft Standards Task Force (Palliative Care),
2. 1st Draft Standards Task Force (Advance Directives), and
3. 1st Draft Reimbursement Task Force.

Ms. Macdonald explained these documents would be the basis for the final report and the focus of the workgroup today. Richard Frieberg provided the workgroup with materials regarding acupuncture.

Mr. Allen noted an error in the 1st draft recommendations regarding Advance Directives and the Meeting Summary from November 14th. Mr. Allen requested that the sentence –“The threshold alternative criteria required to be certified in order to withhold or withdraw life sustaining treatment should be omitted from F.S. 765.” be moved under Alternative Two.

Ms. Macdonald reminded members that today's primary meeting objective is to review and vote on each of the workgroup's recommendations. It was decided that additional issues could be discussed that had not already been listed in their recommendations. Ms. Macdonald advised the members that DOEA may contact them to request assistance in the development of recommendations for the final report. Ms. Macdonald reviewed the final report work plan schedule as follows:

- DOEA will send the 1st draft of the final report to the members on November 8th.
- Workgroup members will submit all revisions to DOEA by December 15th.
- DOEA will incorporate the members' revisions by December 22nd.
- DOEA will deliver the final report to the Governor, Speaker of the House, and the President of the Senate by December 31st.

Ms. Macdonald confirmed that a quorum of 14 members were in attendance allowing the workgroup to proceed as planned to review, revise, and vote on each draft recommendations. Ms. Macdonald suggested that the recommendations be prioritized and that the workgroup start with the least controversial recommendations first. Ms. Macdonald recommended that Dr. Tuch present the standards for Palliative Care recommendations.

Dr. Tuch reviewed the paper entitled “Legislative Recommendation (1st Draft) Standards Task Force (Palliative Care)” dated 11/20/00. The paper listed each of the five issues, the pro’s and con’s of each issue, and recommendations.

Dr. Tuch reviewed with the workgroup the first of five recommendations for palliative care standards (dated 11/20/00).

Issue #1 – Definition for Palliative Care

The lack of definition and common understanding of palliative care and its role in the health care continuum contributes to the underutilization of these services and contributes to unnecessary suffering that many Floridians experience in the last-stages of life.

Background

The Florida Legislature recognizes the continued need to address the quality and availability of humane care for citizens who die each year in our state’s hospitals, nursing homes and communities. In an effort to improve care the task force recommends the following:

Recommendation #1

The workgroup recommends adding the following definition of palliative care to Chapter 765, Florida Statutes:

“Palliative care refers to the comprehensive management of the physical, psychological, social, spiritual and existential needs of patients. It is especially suited to the care of people with incurable, progressive illness.”

Pros

This definition is offered by the “Last Acts “ (Robert Woods Johnson Initiative) as part of national effort to reach a common language and set of precepts for palliative care. Adoption of a formal definition of palliative care in Florida Statute should foster greater understanding, acceptance and more timely application of services to appropriate patients. 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. The workgroup also recognizes that the principles and concepts of palliative care are central to humane medical care and as such, should not be reserved for the last moments of life.

Cons

The workgroup discussed whether to use the word “terminal” or “dying” instead of “incurable, progressive illness” in the definition of palliative care. It was felt that the word dying or terminal would have a connotation of the last few weeks/months of life thereby limiting the period of utilization of palliative care services. Incurable, progressive illness was felt to be more comprehensive and would include for example individuals with such illness as *emphysema* or advanced dementia.

Other Points of Discussion Regarding Recommendation #1

- General geriatric care and palliative care have similarities and it is hard to distinguish between the two;

- Another definition of palliative care considered was from the World Health Organization.
- Hospice and the Workers' Compensation statutes provide a definition of palliative care. Adding this definition to Chapter 765, Florida Statutes, would broaden the definition of palliative care and potentially cause increased costs to the workers' compensation system.
- Concern were raised that members were using the words "end-of-life care" interchangeable with palliative care.
- Palliative care can be appropriate for individuals that are not at end-of-life however have a progressive illness.

A motion was made to vote on inclusion of the definition in F.S. 765 and the motion was seconded.

Further Discussion Regarding Recommendation #1

- Concerns about possible broadening insurance coverage (workers' compensation insurance coverage) and a potential interpretation that the definition will create a mandated benefit of palliative care.
- Suggestion to add language prior to the definition of palliative care that would prevent the definition from mandating a benefit.
- Suggestion that the background paragraph include other definitions of palliative care. The background information will be incorporated into the final report.
- Importance of having consensus when possible.
- Suggestion that the major goals of geriatric care are the same as palliative care.

A motion was made to include the definition listed below in Chapter 765, Florida Statutes. The members unanimously voted to approve the motion. The workgroup recommends adding the following definition of palliative care to Chapter 765, Florida Statutes:

"Palliative care refers to the comprehensive management of the physical, psychological, social, spiritual, and existential needs of patients. It is especially suited to the care of people with incurable, progressive illness."

Dr. Tuch reviewed with the workgroup the second of five recommendations for palliative care standards (dated 11/20/00).

Issue #2- Access to Comprehensive Palliative Care

Access to comprehensive palliative care services across the spectrum of health care settings is limited. There is a need for all health care organizations serving seriously ill and dying patients to ensure availability of palliative care and hospice services.

Recommendation #2

The workgroup recommended that language be added to Chapter 765, Florida Statutes to promote increased access to palliative care. Proposed language should include:

- (a) Individual communities and health care organizations should evaluate the adequacy and availability of local palliative care services to meet the needs of their residents/community;

- (b) Development of reimbursement policies to ensure availability of palliative care and hospice services in all health care settings; and
- (c) Identification and reduction of administrative and regulatory barriers to palliative care.

Pros

Increasing access to palliative care services across the full spectrum of health care settings will enable high quality of care for dying patients in Florida. All health care organizations should review their internal, organizational strengths and weaknesses with regard to the quality of palliative care services offered. Efforts to improve quality of palliative care should be included in an organization's quality improvement programs. The task force also recognizes the need to ensure access to palliative care and hospice services for many Floridians including those uninsured, those living in rural areas and among minority populations. Removing administrative and regulatory barriers to palliative care is essential to improve access to these services.

Cons

Concerns were raised that this would increase the number of *unfunded mandates* and potentially increase the cost of health care or divert resources already inadequate.

A motion was made to adopt recommendation two in regard to access to palliative care and the motion was seconded.

Further Discussion Regarding Recommendation #2

- Significance of the word "evaluate" under item 1.
- Wording of item 1 is problematic because it states health care organizations will evaluate adequacy and availability of palliative care – all hospitals, nursing homes would have to do this.
- Purpose of the recommendation is to stimulate discussion of palliative care within health care settings and encourage a community perspective of dealing with end-of-life care issues including palliative care.
- Suggestion regarding item #1 under recommendation #2, to recommend that an existing community or government program perform an end-of-life care community assessment. Possible Local Health Departments, Local Health Planning Councils, Department of Health or the Department of Elder Affairs.
- Suggestion to strike the word "local" under item 1 in recommendation #2.
- Suggestion that the RWJ End-of-Life Care Grant's coalitions might be able to play a role in assessing the communities needs regarding end-of-life care.
- Concerns were raised regarding the consistency among the diverse local coalitions.
- Using a volunteer based project similar in structure to the Serving Health Insurance Needs of Elders (SHINE) administered by the Department of Elder Affairs.
- Appropriateness of a state agency to sponsor the project.
- Unfunded mandates are not the intent of recommendation #2, rather to promote access and coordination of end-of-life care (existing) resources.
- Concerns about adding more governmental control.

- Need to use existing data (huge amount of data on the subject of palliative care is currently available).
- Suggestion to strike item #2 of recommendation #2.
- Recommendations need to be rewritten
- Suggestion to separate health care organizations and communities in item #1 of recommendation #2.
- Suggestion to include recommendation #2 in intent language.
- Motion to withdraw the motion to approve Issue #2 and table for further discussion after a rewrite of the issue. Suggestion made that before recommendation #2 was tabled that these issues also be considered: a) Objection to use of words in quotes - “to ensure availability” of palliative care and “hospice” in all health care settings; and b) Objection to mandating hospice in all health care settings.

A motion was made to table the issue so further work could be done to rewrite recommendation #2 and the motion seconded. The motion was passed.

It was noted that the agenda should reflect that the meeting would end at 3:00 p.m. rather than 5:00 p.m.

Dr. Tuch reviewed with the workgroup # three of five recommendations for palliative care standards (dated 11/20/00).

Issue #3 – Quality – Palliative Care Standards

The workgroup determined that Florida Statutes does not provide quality of care standards for end-of-life care.

Recommendation #3– Quality – Palliative Care Standards

The workgroup recommended that the following standards be added to Chapter 765, Florida Statutes:

Palliative Care must include an:

1. Opportunity to discuss and plan for end of life care.
2. Assurance that physical and mental suffering will be carefully attended to.
3. Assurance that preferences for withholding and withdrawing life-sustaining interventions will be honored.
4. Assurance that the personal goals of the dying person will be addressed.
5. Assurance that the dignity of the dying person will be a priority.
6. Assurance that health care providers will not abandon the dying person.
7. Assurance that the burden to family and others will be addressed and minimized.
8. Assurance that advance directives for care will be respected regardless of the location of care.
9. Assurance that organizational mechanisms are in place to evaluate the availability and quality of palliative care services.

(Source: American Medical Association (AMA) Elements of Quality Care for Patients in the Last Phase of Life)

Pros

These standards already exist in other parts of Florida Statutes. No additional requirements are necessary. Establishing a comprehensive set of standards under the heading of palliative care will promote more comprehensive efforts to improve and monitor palliative care services. A new community standard can thus be established. The workgroup member, Dr. Susan Acker with AHCA is in the process of developing a matrix to cross-reference current standards and statutory/rule authority. Cross-referencing the recommended language with other Florida Statutes will demonstrate that it is cost-neutral, appropriate, and necessary language.

Cons

No concerns were discussed during the November 13th and 14th meetings.

Further Discussion Regarding Recommendation #3

Member comments regarding the recommendations for palliative care standards be added to Chapter 765, Florida Statutes. Discussion followed:

- Important to note that all of the recommended statements are found in other Florida statutes.
- Important to include in one statute – how we evaluate and plan for end-of-life care.

A motion made to approve recommendation #3 – palliative care and the motion was seconded. Further discussion ensued:

- Discussion of what is meant by item (f) – abandonment of the dying person.
- Suggestion to add item “(j) “Assurance that necessary health care services will be provided”.
- Intent of new item (j) is to not withdraw treatment when indicated and health care services are provided.
- Suggestion to include in the Legislative intent language rather than in specific Florida Statutes.
- Suggestion to include “spiritual care” and “existential care”.
- Suggestion to retain the American Medical Association elements as written and define “mental” elsewhere as well as add “spiritual” and “existential care” in the definition. Possible draft a sentence or two as part of the introduction to the AMA - Elements of Quality Care for Patients in the Last Phase of Life.
- Need to include the psycho-social elements;
- Consensus that the recommendation would be made to include in statute.

A motion was made to amend the language to include psycho-social and spiritual. A motion was then made to amend the amendment to state: “Assurance of the comprehensive management of the physical, social, spiritual and existential needs of patients” to be consistent with the previously agreed upon definition of palliative care.

A motion was made to accept recommendation #3 as amended (b) as stated above and to include item (j) assurance that necessary health care services will be provided. A motion was made and seconded to withdraw the motion to accept recommendation #3.

Further Discussion of Recommendation #3.

- AMA had carefully reviewed the wording of these standards of care and it may not be wise to change.

A motion was made to call the question, seconded and was passed. A motion was made to vote on the amended language in item (b). Discussion ensued:

- Suggestion to take out the word "management".
- Use "carefully attended to" instead of "management".

The motion was voted on and did not pass. An amended motion was then made and seconded for the wording in recommendation (b) to read: "Assurance that the physical, social, spiritual and existential needs of patients will be carefully attended to." The motion was passed with one abstaining vote from Susan Acker with AHCA because the AHCA does not regulate spiritual or existential quality of care issues.

Dr. Tuch reviewed with the workgroup # four of five recommendations for palliative care standards (dated 11/20/00).

Issue #4 – Research

There is a need to fund research and demonstration projects to promote:

- Improved access to end-of-life care especially among uninsured and minority populations; and
- Demonstration projects to evaluate evidence-based approaches to improve palliative care.

Pros

As demonstrated by Robert Wood Johnson Foundation recent report called "Pioneer Programs in Palliative Care: Nine Case Studies", innovative clinical programs with creative reimbursement strategies are being developed nationally. The Department of Health has authority to develop and implement a demonstration project for end-of-life care. Funding for demonstration project could be provided from grants and the legislature. Programs such as the Balm of Gilead Center in Alabama that are budget neutral could be developed.

Cons

The Department of Health has no funding to develop and implement a demonstration project for end-of-life care. Potential concerns were raised about the legislature's willingness to allocate funds for research or demonstration projects for end-of-life care.

Recommendation #4

The workgroup recommended that the legislature fund a demonstration project that would:

- (a) Identify current research relevant to palliative care in Florida communities;
- (b) Enhance quality and access to palliative care and hospice services especially in rural, uninsured and minority communities;
- (c) Develop collaborative research and demonstration partnerships; and
- (d) Disseminate the results of current research.

A motion was made to approve recommendation #4 four regarding the need to fund research and demonstration projects. The motion was seconded and approved without further discussion.

Dr. Tuch reviewed with the workgroup # five of five recommendations for palliative care standards (dated 11/20/00).

Issue #5 - Palliative Care Standards - Education

There is an urgent need to improve awareness, knowledge and skills in palliative care for health care consumers and providers alike.

Pros

Training and education on end-of-life care will assist the patient, patient's families, and professionals confronting end-of-life care issues. Training the public, especially those acting as health care surrogates or proxies for incapacitated individuals will promote more informed decision makers. Public and private funding sources for needed educational tools, for educating the public on end-of-life care will be sought. The Department of Elder Affairs "Shine Program" could be used as a model for creating a volunteer program to help educate the public.

Cons

No objections were mentioned. Concerns about funding an on-going public education program were discussed.

Recommendation #5: Palliative Care Standards - Education

PUBLIC

1. Create a targeted and culturally sensitive education or "training" program on palliative care that would be available in all communities. A public relations effort and associated training to raise awareness of and improve the skills of surrogate and proxy decision makers should be promoted. The program components should include:
 - a. Consumer choices and responsibilities,
 - b. Expectation for access to effective pain management and palliative care in all health care settings,
 - c. Advance Directives and Surrogate/Proxy decision makers, and
 - d. Targeting elders, their children, and caregivers in a public relations effort to improve their decision-making.

PROFESSIONAL

1. Encourage educational institutions to establish or enhance curricula to rapidly improve training in palliative care for physicians, nurses, counselors, social workers, pharmacists, or any other end-of-life care provider.
2. Encourage the use of established curricula in CME and CEU.
3. Encourage the development of palliative medicine fellowship program in the four medical schools in the state.
4. Encourage professional regulatory boards to adopt appropriate rules, standards and guidelines to evaluate the delivery of palliative care.

Further Discussion of Recommendation #5.

A motion was made to table recommendation #5 regarding the need to improve awareness, knowledge and skills in palliative care for health care consumers and providers for further rewrite. Issues discussed included:

- Education should be a statewide effort
- Who would be responsible for the education model?
- Legal aspects of guardianship education
- Role of the state agencies
- Concern about duplication of effort
- Use of existing resources

The motion to table the discussion of recommendation #5 pending further rewrite was seconded.

Ms. Macdonald asked the workgroup to continue the discussion on the next set of Legislative Recommendation (1st Draft), Standards Task Force (Advance Directives) paper. Ms. Macdonald asked Mr. Bill Allen to lead the discussion. Mr. Allen requested that the members turn to page 4 of the Recommendations for Advance Directive Standards.

Two alternatives were presented in the paper on Advance Directives.

Alternative One:

Substituted judgment must be the preferred standard of decision-making used by health surrogates, durable powers of attorney for health care (DPAH), and proxy decision-makers, but when there is no indication what the principal would have chosen, proposed or currently in place treatments may be withheld or withdrawn by the surrogate, D.P.A.H., or proxy's decision under a best interest standard.

Issues discussed concerning alternative one included:

- Reiterated the draft meeting summary for November 14, 2000 should be revised to move the statement "The threshold..." located in alternative one to alternative two. The meeting summary will be corrected.
- Best interest standard is a secondary standard – does not apply to Section 4 where there is no indication of decision maker.
- Need to spell out durable power of attorney health care (D.P.A.H.)
- Suggested wording change in alternative one to read "treatments currently in place"
- Definition of "best interest". "Best interest" is defined different from case to case. A draft definition of best interest was given.
- Definition of "substitute judgment" not found in the definitions section of Chapter 765. Florida Statutes. Other states, such as Maryland, have a definition for "best interest".
- Need to have a way to make decisions without putting people in jeopardy of bad decisions.

- “Best interest” does not apply to those people acting on behalf of someone they don’t know.
- Broadens the standard for those acting on behalf of someone they know but don’t have first hand knowledge of the wishes for a specific treatment decision.
- Medical profession faces these issues all the time.
- Guilt associated with decision-making.

A motion was made to accept this recommendation, was seconded and approved. Alternative #1 will be considered recommendation #1 for advance directive standards.

The workgroup took a brief lunch break and agreed to reconvene at 12:45 p.m. Some members agreed to have a working lunch to revise recommendations #2 and #5 from the Palliative Care discussion.

The workgroup reconvened at 12:50 p.m. Ms. Macdonald asked Dr. Smith to act as the parliamentarian and he agreed. Ms. Macdonald recommended that the workgroup consider having a 2 hours telephone conference all on December 15, 2000 for the purpose of finalizing any outstanding business. The workgroup members agreed that Ms. Macdonald should publish an End-of-Life Care Workgroup telephone conference notice in Florida Administrative Weekly (FAW) for December 15th from 10:00 am to noon. The purpose of the telephone conference is to ensure the workgroup can finalize any outstanding issues prior to the submission of the final report to the Governor, Speaker of the House, and the President of the Senate. Ms. Macdonald requested that Bill Allen continue his presentation of the recommendations for advance directive standards.

Bill Allen reviewed Alternative Two with the workgroup.

Alternative Two:

The threshold alternative criteria required to be certified in order to withhold or withdraw life-sustaining treatment should be omitted from Chapter 765. Florida Statutes.

If these criteria are not omitted, “end stage condition” definition should be changed to read as follows:

Section 765.101(4): End stage condition means a condition that is caused by injury, disease, or illness which has resulted in severe and permanent deterioration, indicated by incapacity and significant physical dependency, and for which the patient, resident, or authorized representative would deem curative treatment to be more of a burden than a benefit.

Discussion

- The threshold criteria, terminally ill, end stage condition and persistent vegetative state needs to be stated in the report.
- Difficulty in changing the threshold criteria.

Ms. Macdonald reiterated to the workgroup members that the department might need their assistance in completing this report on time. Mr. Kelley was present and reminded that the report is a product of the workgroup; and that the workgroup will vote on the recommendations instead of making arbitrary decisions. The workgroup was asked if anyone interpreted the mission as outlined in the law differently. The inclusion of dissenting views in

the report was discussed. It will be important for the background of these recommendations to be presented in the final report.

Other issues discussed were:

- Making changes to the law will not endanger the poor or disenfranchised,
- Legal protections are in place,
- Objection to the use of the words “permanent deterioration, indicated by incapacity” – noted that these were not changed from current statute,
- Favor for use of word “significant”, and
- Suggested the word “progressively” be added.

A motion to amend the wording of Alternative Two (Advance Directive Standards) to:

“End stage condition means a condition that is caused by injury, disease, or illness which has resulted in progressively severe and permanent deterioration and for which the patient, resident or authorized representation would deem curative treatment to be more of a burden than a benefit.”

The motion to amend Alternative Two (Advance Directive Standards) was seconded and approved.

Mr. Allen presented a new issue related to advance directives/ do not resuscitate order (DNRO). Mr. Kelley and Mr. Allen reported that during a recent presentation at the Elder Institute, case managers in the audience stated in some cases law enforcement and fire fighters did not honor DNRO's. The case managers thought the reason was that law enforcement and fire fighters do not have protection from liability and may not have been properly educated about DNRO's portability.

Discussion New DNRO Issue:

- Need to educate families regarding DNRO.
- Public safety (law enforcement or fire departments) may be the first responders.
- Not ready to tackle this issue without much more discussion.
- Suggestion that the appropriate bodies associated with these public safety agencies make recommendations on these issues.
- Ms. Travis stated some military physicians are excluded from being able to write a DNRO because they are not licensed by the State of Florida.

Ms. Macdonald requested that Freida Travis submit a brief summary of the issues regarding DNROs raised by Mr. Allen and Mr. Kelley. This information will be placed in the report.

Dr. Smith requested that the workgroup return to the need for the workgroup to finish the vote on the Advance Directive Standard recommendations. ***A motion was made to approve the advance directives recommendation #2 as amended. The motion was approved.***

Mr. Allen raised the issue of “may” or “must” in the DNRO and it was recommended that this be tabled for discussion until the end of the meeting if time permitted. It was noted that all issues raised would be reflected in the report.

Ms. Macdonald requested that the workgroup resume discussion of the previously tabled recommendation #2 and #5 on “The Legislative Recommendations (Revised 1st Draft), Standards Task Force (Palliative Care).

Recommendation #2- Access to Comprehensive Palliative Care

The following amendment to recommendation #2 for Palliative Care standards were discussed:

“State health care organizations and individual health care entities should evaluate:

- 1) The adequacy of palliative care services;
- 2) The reimbursement policies which ensure availability of palliative care;
- 3) Administrative and regulatory barriers to palliative care.

Other workgroup comments included:

- Narrative should include identification and reduction of regulatory barriers.
- Health care entities can only evaluate within the purview of their own agency
- Suggest adding words “their”, “relevant” and “applicable”

A motion was made and seconded to approve the amendment as follows:

“State health care organizations and individual health care entities should evaluate:

- 1) The adequacy of their palliative care services;
- 2) The relevant reimbursement policies which ensure availability of palliative care;
- 3) Applicable administrative and regulatory barriers to palliative care.

Ms. Macdonald called for a vote on the motion to approve amended recommendation #2 for palliative care standards. The motion was approved unanimously.

Recommendation #5: Palliative Care Standards - Education

This recommendation involves improving awareness, knowledge and skills in palliative care for health care consumers and providers. The following is the *recommended* language amendment to recommendation #5 –palliative care standards under item (a) 1):

“The appropriate state agency identify and coordinate existing training programs and materials on palliative care that would be available in all communities and collaborate with programs such as “The Partnership” to promote community awareness and skills of surrogate and proxy decision makers. Determine the need for and establish new programs on training of surrogate and proxy decision makers to ensure ongoing programs meet community needs.”

Discussion:

- The responsible entity should be left to the legislature to determine.

A motion was made to add “the legislature will name a department to”, the motion was seconded and approved. Dr. Smith moved that a vote be taken to approve recommendation #5 palliative care standards.

Further discussion ensued as follows:

- Item (b) 2) – What are the established criteria for CME and CEU?
- Item (b) 4) – Is the regulatory board the correct entity to do this?
- Does the education requirement apply to substitution of “end-of-life care ” or “palliative care?” Both are stated in law.
- Suggestion to substitute “teaching” for “evaluate” in (b) 4)
- Concern about who has responsibility and it being too broad
- In item (b) 4) – want to establish an expectation that professional organizations must recognize the importance of palliative care
- Substitute palliative care
- Need to include language to increase awareness
- Realization that both palliative care and end-of-life care are mentioned as a substitute for the continuing education requirement – just need to expand the base for who it applies to
- Recommendation to eliminate item (b) 4)

A motion was made to amend recommendation #5 – palliative care standards as follows

Amend (b) 2) to professional. Delete (b) 4) as follows: 2) Encourage professional regulatory boards to adopt appropriate rules, standards and guidelines to evaluate the delivery of palliative care.

A motion was made and seconded to approve recommendation #5 –palliative care education standards.

Dr. Tuch asked that workgroup to revisit recommendation #3 - palliative care quality standards. Dr. Tuch restated Dr. Acker's comments in the morning that AHCA has to abstain because the workgroup amended the AMA standards to include “spiritual and existential”.

A motion was made to remove the words “existential and spiritual” in Issue 3.**Discussion ensued as follows:**

- AHCA will not be able to endorse this motion because of AHCA’s directive not add any regulations that would potentially increase in costs.
- Need for a strong statement in the beginning narrative if these words are removed.
- Relates to recommendation made earlier to include “necessary health care be provided”
- Recommendation to revert back to physical and mental.
- Recommendation to add (j) – “Assurance that necessary health care be provided”.

A motion was made, seconded, and approved to revert to original language for Issue 3, item (b) and add (j) as follows:

- (b) Assurance that physical and mental suffering will be carefully attended to.
- (j) Assurance that necessary health care services will be provided.

Ms. Macdonald asked the workgroup to review the paper entitled “Legislative Recommendations (1st Draft), Reimbursement Task Force” and dated 11/17/00.

Issue #1 – Reimbursement

There is a need for end-of-life care education for individuals in the private, public and professional sectors. There is lack of reimbursement and incentive for providing this type of education to all populations, and thereby bringing better care of the dying and treating death as a part of human experience.

Background

The hospice movement has been at the forefront of advancing education for the public and professional sectors in end-of-life palliative care. Other professionals are actively developing curricula on end-of-life care. This type of health care includes physical, emotional, spiritual and social aspects of patient care as well as support and education for the caregivers and has been seen as effective and needs to be incorporated into wide educational efforts.

Pros

This country has been focused socially and medically, since WWII, on advances in curative treatments, ways to keep people living longer and healthier and battling heretofore-deadly diseases with vaccines, antibiotics and a host of internal and external ways to defy death. Now this is an ingrained culture and the naturalness of death and the ways to help people deal with chronic and terminal infirmities has been ignored to the point that we have become a death denying population. We do not prepare for the reality for ourselves or those we love to avoid futile treatment and provide comfort care for those incurable conditions. In living longer, due to advances in knowledge, treatments, and technology, we are now facing more complex decisions about dying and the prolongation of life.

Cons

There are educational units being included in medical schools on end-of-life care and there are Internet sites that are replete with information on death, dying and other end of life issues. Popular news and information magazines are carrying articles on the subject in an increasing number. A television series was recently funded, produced and shown nation-wide on these issues. People are beginning to understand the need for being prepared for the end of their lives and to accept comfort care.

Recommendation #1- Reimbursement

Provide adequate public funding for the public at large and health care professionals for education on end-of-life care, with specific initiatives for rural and other under served populations as provided in section 765.102 (5), Florida Statutes.

A motion was made, seconded, and approved to approve recommendation #1 – reimbursement.

Issue # 2 – Reimbursement

There are many settings in which individuals live as they are provided end-of-life care: private home with no outside care, private home with hospice or home health care, long term care facility, acute care hospitals, assisted living facility, free-standing hospice residence or inpatient facility.

People deserve to have choices of where and how they receive care at the end of life. There should be financial and educational incentives for developing a credible continuum of care for all people at the end of life.

Background

There have been studies over the last several years concerning patients who are diagnosed with terminal conditions and the type of treatments they have received in medical institutions. Many individuals who are facing the end of their lives have not received the type of treatments that reflected their own wishes to avoid unwanted life-prolonging therapies and to receive pain and symptom relief to experience quality of life for whatever amount of time is theirs to enjoy.

Pros

We need to preserve the medical programs and other institutions available in this country. There can be a workable continuum developed to enhance care at the end of life. Health care facilities/programs could receive credit for having such a continuum of care. Long-term Care/Nursing Homes should work cooperatively with Hospices to improve care for all residents.

This relationship could be considered as a component for Gold Seal provider. Educational continuing medical education (CME) and continuing education units (CEUs) could be provided as incentives. It could avoid the impoverishment of families. Day care programs could work cooperatively with Hospice programs; acute care hospitals could develop similar working relationships with Hospices to develop and maintain palliative care programs.

Cons

There are enough existing facilities to handle better end-of-life care. Physicians, administrators, and all other appropriate professionals should maintain their own education and implementation of improved care for end of life should be a constant. There might be an additional funding problem.

Recommendation #2 - Reimbursement

The workgroup recognizes that health care facilities are a vital and frequent component for end-of-life care in Florida and recommends that the Legislature initiate a study to identify the methods and costs of high quality end-of-life care in all types of Florida health care facilities.

A motion was made, seconded to approve recommendations #2. The workgroup voted to approve recommendation #2 – reimbursement.

Issue 3 - Reimbursement

All health care professionals should be able to substitute palliative care education for the currently required HIV/AIDS continuing education requirement.

Background

Statutory changes to remedy a technical oversight.

Pros

There was a technical oversight omitting Certified Nursing Assistants from the legislative allowing for the substitution stated above. This oversight should be corrected. This has no fiscal impact.

Cons

CNAs should not be included in this substitution.

Recommendation #3 – Reimbursement

Recommend that sections 456.031, and 456.033, F.S., be amended to include Certified Nursing Assistants.

Discussion

Issue three relates to all health care professionals having the right to substitute palliative care education for the currently required HIV/AIDS continuing education requirement.

- Concern that this recommendation will cover all health professionals – the consensus of the group is that it would cover all who were inadvertently left out in previous legislation.
- Research was done to ensure that all groups are covered.
- Issue should also be amended to reflect domestic violence as another substitute option for HIV/AIDS.

A motion was made to approve the amended language to include domestic violence. The motion was seconded and approved.

Issue #4 - Reimbursement

The above regulations are (l) in conflict with Florida Statutes governing hospice care. These statutes were made law in 1977 prior to Health Care Finance Administration's (HCFA's) financing of hospice care through a special per diem benefit in 1982. This conflict provides a dilemma for Florida physicians in referring their Medicare patients and their HMO, private insurance or self-pay patients. The major issue is that the six-month requirement is a barrier to access as physicians tend to refer patients who have very short life expectancy (days or weeks) in order to avoid exceeding the six months. Although there are re-certification periods it is the initial limit of six months or less that is the barrier to admission.

Background

The HCFA Medicare regulations include a rule that requires physicians to certify that a terminally ill patient has a prognosis (expected length of life) of six months or less to qualify for hospice care.

Pros

All terminally ill patients whom their physicians recognize the need for hospice care should be allowed to follow the Florida Statute guidelines on referring all of their appropriate patients. All patients would be treated the same. It would allow the patients and their family members the benefit of hospice care over a longer period of time thereby easing their pain, avoiding emergency room admissions, hospitalizations and generally improving their quality of life for a somewhat longer period of time. This would also enable the continuum of health care to be initiated at an earlier time in the patient's life.

Cons

This would confuse people because they know about the six months. There are re-certification periods to allow longer stay in hospice. It will be hard to get HCFA to do it.

Recommendation #4

The Florida Legislature recommends to the Health Care Finance Administration (HCFA) that, as specified in section 400.60(10), F.S., the initial Medicare and Medicaid Hospice certification period be for one year or less.

Discussion

This issue related to the certification that a terminally ill patient has a prognosis (expected length of life) of six months or less to qualify for hospice care.

A motion was made to approve the issue and seconded. Discussion ensued as follows:

- The present system of initial six-month certification period and re-certification process for hospice care eligibility is workable and does not need to be revised.
- Confusion about access because they don't understand the eligibility re-certification process.
- Statistic of 50% of hospice patients die within a month of receiving hospice services.
- Issue of referral for hospice service not the re-certification process.
- Concern about eligibility for hospice being one year or less.
- Physicians are concerned about being *charged with fraud* if patient receives hospice services for longer than one year.
- Families do not always choose hospice because of concerns for treatment options and acceptance of prognosis.

A motion was made to approve the issue. It was seconded and failed.**Issue #5 - Reimbursement**

Complimentary/alternative medicine and ancillary-care professionals should be reimbursed as an add-on component to Medicaid for end-of-life care.

Background

The Panel for Study of End-of-Life Panel stated that there be a continuum of care across all health care providers, which included alternative/complimentary medicine. DOI is available to provide insurance and long-term care policy information on this subject.

Pros

Complimentary/alternative medicine/therapies are utilized by various populations in the treatment of pain and other physical and emotional conditions. Complimentary/alternative medicine/therapies are an added benefit to patients of all ages and circumstances and as such could be a useful addition to the continuum of care at the end of life. Complimentary/alternative medicine/therapies can be relaxing for patients and often very effective at the end of life.

Cons

These therapies are already being used in end-of-life care, reimbursed through various means including Hospices when patients request these methods and alternatives and their physicians approve. There could be an additional cost to the state for this inclusion.

Recommendation #5 - Reimbursement

Recognize health care professionals licensed under chapters 457, 458, 459, 460, and 464, F.S., providing end-of-life care services, and reimburse them, under the state Medicaid methodologies and insurance plans, in accordance with sections 627 and 641, F.S.

Discussion

The issue of complimentary/alternative medicine and ancillary-care professional should be reimbursed as an add-on component to Medicaid for end-of-life care. ***A motion was made to adopt the issue. Discussion ensued as follows:***

- Concern for the word “relaxing” in the Pros section.
- Medicaid is so deficient now that adding more requirements would cause an undue burden.
- Concern that current funding levels do not cover immunizations for children.
- Services need further evaluation for cost effectiveness.
- Concern about current average Medicaid expenditures of \$2,000 per person being insufficient for good care.
- Pharmacies are not being adequately reimbursed under Medicaid now.
- Concern for redirecting current funding to other providers with the shortage of dollars in Medicaid.
- Medicaid is paying for acupuncture services currently in other areas of the country. A summary of the cost effectiveness and a list of the states, which reimburse for acupuncture are included in the materials hand out today to member by Richard Freiberg.
- No additional funds would be needed to fund these services – would be swapped for other services currently being provided.
- Most medicine is paid for out of pocket and this would cause a cost shifting.

A motion was made to vote on endorsement of the issue by the workgroup. The motion failed to pass.

An alternate suggestion was made to amend recommendation #2 to include asking the legislature to conduct a cost analysis of the issue – complementary or alternative medicine. The motion was made, seconded and approved to add language to issue two to recommend a cost study be done.

Ms. Macdonald reminded the workgroup that the first draft of the final report would be sent to them on December 8th. The workgroup members are to provide comments in writing to DOEA by December 15th. Also, Ms. Macdonald reminded the members that DOEA will coordinate the December 15th telephone conference from 10:00 to noon. The purpose of the telephone conference will be to finalize any outstanding business. An inquiry was made if the draft report could be made available on the DOEA's website and the workgroup was advised that this would be reviewed with the appropriate staff. The meeting was adjourned at 3:10 p.m.

Find below a brief description of documents provided to the End-Of-Life Care Workgroup on November 27th, 2000 and prepared by Richard Freiberg, D.O.M., D.Ac., Dipl.Ac., Florida State Oriental Medical Association. Workgroup members were made aware that these materials would be made available upon request.

- **Tab 1** – Background, Of Reimbursement Task Force Issue #5. Describes the preliminary Pros, Cons, and Recommendation.
- **Tab 2** – Primary Providers of Non-traditional modalities. Discusses Florida Acupuncture Physicians and their role in being the primary providers of complementary, alternative & non-traditional health care and other issues.
- **Tab 3** – MEDICAID already pays for Acupuncture in eight states. Lists the major states where MEDICAID reimburses Acupuncturists directly.
- **Tab 4** – Department of Health & Human Services. Oct. 3, 2000 Program Assistance Letter from the Assistant Surgeon General to integrate complementary and alternative health practices with conventional medicine at Bureau of Primary Health Care (BPHC) supported programs specifically including acupuncture, herbs, homeopathy, and other CAM services.
- **Tab 5** – Ninth District Circuit Court's Decision - *Every category provider* Law. Notice regarding the final ruling in Washington Physicians v. Gregoire upholding the validity of Washington State's *Every Category of Provider* law, RCW 48.43.045.
- **Tab 6** – Testimony on Alternative Medicine before U.S. Senate Dr. Harvey Kaltsas (Doctor of Acupuncture & Acupuncture Physician) testimony regarding the benefits and cost effectiveness of acupuncture.
- **Tab 7** – The Future of Health Care Article on CAM becoming mainstream within the next five years.
- **Tab 8** – Acupuncture Research Cost effectiveness in *AVOIDANCE OF KNEE SURGERY*
- **Tab 9** – Acupuncture Research. Cost effectiveness in stroke patients *DECREASED DAYS IN HOSPITAL & REHABILITATIVE NURSING HOME.
- **Tab 10** – Acupuncture Research. Cost effectiveness for chronic low back pain *QUICKER RETURN TO PHYSICAL LABOR*

- **Tab 11** – Acupuncture Research. Cost effectiveness in patients with severe angina pectoris. *AVOIDANCE OF SURGERY, FEWER HOSPITAL VISITS/GREATER RETURN TO EMPLOYMENT*
- **Tab 12** – Acupuncture Research - Near END-OF-LIFE. Evidence for efficacy for CAM including acupuncture benefit for Management of Pain Dyspnea, Nausea and Vomiting.
- **Tab 13** – Acupuncture Research. Pain-relief and movement improvement by acupuncture after ablation and axillary lymphadenectomy in patients with mammary cancer.
- **Tab 14** - Acupuncture Research. Relief benefits of cancer-related breathlessness.
- **Tab 15** – Acupuncture Research. Relief for patients in hospital-based home care suffering from xerostomia.
- **Tab 16** – Acupuncture Research. Treatment benefits of Paralysis Due to Central Nervous System Damage.
- **Tab 17** – Low -Level Laser Acupuncture for Carpal Tunnel Syndrome.
- Effectiveness in treating Carpal Tunnel Syndrome.
- **Tab 18** – Acupuncture in the Painful Crises of Sickle Cell Anaemia. Documented pain relief.
- **Tab 19** – Florida Medical Association attacks Acupuncture Physician*s use of title.
- **Tab 20** – Florida Medical Association attacks the core of Acupuncture Practice Act. Ongoing litigation showing the continued resistance by competitive health care providers in the full acceptance of Florida Acupuncture Physicians thereby inhibiting the availability to the public of this legislated *healing art*.
- **Tab 21** – Letter written to BCBSFL*s by Tom Gustafson. Is there Anti-competitive implementation of the Health Care policy in regard to state employees and Licensed Acupuncture Physician providers?
- **Tab 22** – CPT*s (AMA) lack of writing full Electronic Code sets. Lack of codes for Acupuncture Physicians and other CAM providers prevent them from conforming with HIPAA mandate for the Electronic Commerce migration in Oct. 2002. Alternative systems such as the ABC Codes which are already approved by the American Nurses Association yet their acceptance is being blocked at many levels.
- **Tab 23** – JAMA Article 7/26/2000. *Doctors are the Third Leading Cause of Death in the U.S. causing 250,000. Deaths Every Year* - article reviewed by Joseph Mercola, D.O.
- **Tab 24** – How Safe is Conventional Health Care? Summary of excerpts from JAMA, New England Journal of Medicine addressing why this country is in a healthcare crisis.
- **Tab 25** – What You Don*t Know About the Long Term Effects of the Most Popular Drugs.
- **Tab 26** – Ineffectiveness of Mammography compared to physical examinations. Thirteen year Canadian study of 40,000 women proving that mammograms were no more effective in preventing deaths from breast cancer than periodic physical examinations for women in their 50*s.

**END-OF-LIFE CARE WORKGROUP
TELEPHONE CONFERENCE SUMMARY**

Friday, December 15, 2000, from 10:00 am to 12:00 pm

Telephone Conference Participants

Susan Acker, Agency for Health Care Administration (AHCA)
Samira Beckwith, Florida Hospices and Palliative Care, Inc. (FHPC)
Cathy Emmett, ARNP, Florida Nurses Association (FNA)
Richard Freiberg, DOM, D.A.C., Florida State Oriental Medical Association (FSOMA)
Julia Herndon, Florida Association of Insurance and Financial Advisors (FAIFA)
Marshall Kelley, Department of Elder Affairs, (DOEA), **Facilitator**
Linda Macdonald, Department of Elder Affairs (DOEA)
Jim Powers for Peggy Ann Zaenger, Florida Pharmacy Association (FPA)
Marshall Seiden, Florida Association of Homes for the Aging (FAHA)
Kelley Skidmore for Senator Ron Klein Florida Senate
Alvin E. Smith, M.D., Florida Medical Association (FMA)
Peg Terbeek, Florida Life Care Residents Association (FLiCRA)
Howard Tuch, M.D., Florida Health Care Association (FHCA)

Telephone Conference Observers

Bill Allen, J.D., M. Div., Associate Professor, University of Florida, Bioethics, Law and the Humanities Program; and the Florida Bioethics Network
Francie Pleadl, Florida Medical Association (FMA)
Cam Fentriss, Florida Hospices and Palliative Care, Inc. (FHPC)

Workgroup Members Absent

Dr. JoAnne Bujnoski, Florida Osteopathic Medical Association (FOMA)
Representative Heather Fiorentino, Florida House of Representatives
George Mayzell, M.D., Florida Association of Health Maintenance Organization (FAHMO)
Henry Pearson, Florida Assisted Living Association (FALA)
Freida B. Travis, Department of Health (DOH)
Susan White, M.D., Florida Hospital Association (FHA)
Peggy Ann Zaenger, Florida Pharmacy Association (FPA)

Call to Order

Marshall Kelley and Linda Macdonald called the meeting to order at 10:00 a.m. Mr. Kelley and Ms. Macdonald facilitated the workgroup's telephone conference for the purpose of resolving outstanding workgroup issues specifically the draft final report. Ms. Macdonald reviewed workgroup member's comments on the draft final report received to date. Workgroup members recommended numerous technical changes to the draft final report.

The workgroup members agreed to the following substantive changes to the draft final report:

- Where the term “palliative care” is used insert the words “end-of-life and palliative care” (as appropriate).
- Strike the words “and minimize” after the word “addressed” from standards of palliative care #7 on pages 3 and 15.
- Strike the word “fund” before demonstration project and insert the word “initiate” on pages 4 and 17.
- Strike the words “substituted judgment” and insert the words “best interest” on pages 4 and 13.
- Strike the word “curative” and insert the words “life prolonging” on pages 5 and 13.
- Strike the words “adequate public funding for the” and the word “for” before the word education on pages 5 and 8.
- Strike the words “nursing homes” and insert “settings” on page 8.
- Insert the words “end-of-life care specialist” after the word “Hospices” on page 8.
- Strike the words “add language to Chapter 76, Florida Statutes,” and the word “study” and insert “demonstration project to” on pages 5 and 9.
- Insert Florida Statute citations of hospice in Table 3 “Elements of Quality Cross Referenced in Florida Statutes”.
- Insert a sentence similar to “This section includes workgroup members non-concurring and individual opinions.” on page 19.

The workgroup members then discussed the letter dated December 6, 2000, from Aging with Dignity. After much discussion, the workgroup decided not to change the recommendations in the report.

Ms. Macdonald explained that today’s revisions to the recommendations would be incorporated into the final report and subsequently the final report will be submitted to the Governor, President of the Senate, and Speaker of the House. Ms. Macdonald noted that by law (chapter 2000-295, Laws of Florida) the End-of-Life Care Workgroup is authorized to meet through May of 2001. Kelley Skidmore stated that if Senator Klein needs the workgroup’s assistance during the 2001 Legislative session, they would contact DOEA to reconvene a workgroup meeting. The End-of-Life Care Workgroup’s telephone conference was adjourned at noon on December 15th.

Appendix C: Brief Summary of Guardianship of Estelle M. Browning, State of Florida, Petitioner, V. Doris F. Herbert Prepared by Bill Allen, J.D.

IN RE: GUARDIANSHIP OF ESTELLE M. BROWNING, STATE OF FLORIDA,
Petitioner, v. DORIS F. HERBERT,

[*7] We have for review. In re Guardianship of Browning, 543 So.2d 258 (Fla. 2d DCA 1989),
[**2] in which the district court certified the following question as one of great public
importance:

Whether the guardian of a patient who is incompetent but not in a permanent [*8]
vegetative state and who suffers from an incurable, but not terminal condition, may exercise
the patient's right of self-determination to forego sustenance provided artificially by a
nasogastric tube? Id. at 274. n1 We answer the question in the affirmative as qualified in this
opinion.

I. THE FACTS

On November 19, 1985, a competent Estelle Browning executed a declaration that provides, in
part:

If at any time I should have a terminal condition and [**3] if my attending physician has
determined that there can be no recovery from such condition and that my death is
imminent, I direct that life-prolonging procedures be withheld or withdrawn when the
application of such procedures would serve only to prolong artificially the process of dying.
In addition, Mrs. Browning stipulated that she desired not to have "nutrition and hydration
(food and water) provided by gastric tube or intravenously.

The consensus of the medical evidence indicated that the brain damage caused by the
hemorrhage was major and permanent and that there was virtually no chance of recovery.
**Death would occur within seven to ten days were the nasogastric feeding tube removed.
However, Mrs. Browning's life could have been prolonged up to one year as long as she
was maintained on the feeding tube and assuming the absence of infection.**

II. A COMPETENT PERSON'S RIGHT OF PRIVACY

We also agree with the district court that Mrs. Browning's fundamental right of self-
determination, commonly expressed as **the right of privacy, controls this case.**
In Florida, we have recognized that **this fundamental right of privacy has been expressly
enumerated in article I, section 23 of the Florida Constitution**, which provides "an explicit
textual foundation for those privacy interests inherent in the concept of liberty."

Thus, we begin with the premise that everyone has a fundamental right to the sole control of his or her person. As Justice Cardozo noted seventy-six years ago:

Every human being of adult years and sound mind has a right to determine what shall be done with his own body. *Schloendorff v. Society of New York Hosp.*, 211 N.Y. 125, 129-130, 105 N.E. 92, 93 (1914). An integral component of self-determination is the right to make choices pertaining to one’s health, including the right to refuse unwanted medical treatment.

We conclude that a competent person has the constitutional right to choose or refuse medical treatment, and that right extends to all relevant decisions concerning one's health.

III. AN INCOMPETENT PERSON’S RIGHT OF PRIVACY

Having determined that a competent person has the constitutionally protected right to choose or reject medical treatment, we consider whether this right is lost or diminished by virtue of physical or mental incapacity or incompetence. n9 We previously determined that it is not. In *John F. Kennedy Memorial Hospital, Inc. v. Bludworth*, 452 So.2d 921, 923 (Fla. 1984), **this Court held that an incompetent person has the same right to refuse medical treatment as a competent person.**

In this instance, however, Mrs. [**33] 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.” Thus, the only question was whether the conditions established by Mrs. Browning in her declaration were satisfied.

The trial court found that death would occur within four to nine days after removal of the nasogastric feeding tube. Therefore, Mrs. Browning’s life could only have been sustained beyond that time by the administration of artificial, intrusive medical measures.

Under those circumstances, Mrs. Browning’s death was imminent as we construe her express written intent. In addition, all the doctors [**34] agreed that Mrs. Browning suffered permanent brain damage and the medical testimony established that there was no hope that she would recover from her condition. We are satisfied that clear and convincing evidence existed to support a finding that Mrs. Browning suffered from a terminal condition. Under these circumstances, the surrogate was correct in instructing Mrs. Browning’s health care providers to discontinue all life-sustaining procedures in accordance with Mrs. Browning’s wishes.

-----Footnotes-----

n10 This opinion addresses only those persons who are mentally and physically incapacitated and are being sustained by artificial means. We do not address those who are mentally incapacitated but physically are in good health.

Appendix D: Panel For the Study of End-of-Life Care Final Report Executive Summary

Final Report Executive Summary (07/26/99)

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 planning 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 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.
 - * 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.

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