

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

Interim Report

Submitted by:

**Panel for the Study of End of Life Care
January 31, 1999**

Administered by:

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January 31, 1999

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

The 1998 Florida Legislature created, in CS/CS/HB 3387, the Panel for the Study of End-of-Life Care. This 22 member panel was directed to study issues related to the care provided to persons as they near the end of their lives. In particular, the group was requested to consider the issues of pain management, advance directives, and regulatory and fiscal barriers and incentives which impact on end-of-life care. During these last months, I have been honored to be asked to Chair this Panel and help facilitate its work on this most important area of public policy. The Panel has held meetings across this state and received important public input on these issues. The interim report presented to you today is the result of that public input on these key issues. It reflects the work-product of numerous individuals and organizations who have spent countless hours to fulfill the Legislature's mandate and hopefully begin the process of answering the public's concerns on these issues.

The Panel looks forward to continuing its work in the coming months and bringing forth additional suggestions through its next report due on August 1 of this year.

Sincerely,

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

Executive Summary

The Panel for the Study of End-of-Life Care has been constituted according to the membership provisions in the enabling legislation and given its specific charge by the Florida Legislature (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.

The Panel's recommendations for changes in legislation, regulations, education and care practices that address the inadequacies of end-of-life care in Florida include the following:

Regarding Pain Management and Palliative Care:

- .. That all persons should have access to effective pain management and palliative care;
- .. That standards for pain management, management of other distressing clinical symptoms at the EOL, 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;
- .. That the Agency for Health Care Administration and the Department of Elder Affairs should be directed to develop or adopt reasonable standards to monitor the implementation and effectiveness of pain and palliative care strategies;
- .. That pain management to achieve acceptable comfort for people at the end of life, when provided in full compliance with Section 458.326 of the Medical Practice Act (the Intractable Pain Statute), should be construed as meeting the standard of medical care;
- .. That health care boards adopt rules concerning guidelines for pain management;
- .. That health care boards develop and/or promote educational programs to disseminate information regarding these rules and practices;

- .. That professional education offered in medical, nursing, social work, and pharmaceutical schools throughout the state review and implement curricula designed to train providers in principles of pain management and palliative care;
- .. That materials and courses be designed to educate practicing health-care professionals on appropriate standards of pain management and palliative care;
- .. That specialized training programs focused on appropriate EOL care be promoted;
- .. That increased and earlier referral to Hospice for appropriate patients be promoted;
- .. That a program on end-of-life care be established at the Pepper Institute on Aging and Public Policy to serve as a center of research and policy analysis on EOL care in the state;
- .. That a state-wide public education campaign to improve understanding of palliative care, enhanced access to Hospice and palliative care services and understanding of advance care planning and advance directives be created;
- .. That culturally sensitive education programs to improve EOL care in minority communities be created;
- .. That the Florida Legislature should designate specific funding for studies designed to determine the clinical needs, costs and services available to Floridians dying at home, in Hospice, in the hospital, in assisted living centers, in nursing homes, and to those without health care insurance;

Regarding Advance Directives:

- .. That the Florida Legislature remove from F.S. 765 the requirement that a person be “terminally ill” before life-prolonging procedures can be withheld or withdrawn;
- .. That a standardized and portable Do Not Resuscitate Order (DNRO) form that can be used in all patient settings be developed and policy and procedures be created to implement effective use of this form;
- .. That the Legislature provide for “demonstration projects” by local communities in conjunction with Department of Health to develop mechanisms for the implementation of pre-hospital DNROs;
- .. That an assessment and evaluation of one physician as to a patient’s capacity be sufficient for those who have legally executed advance directives; that two physicians or one physician and an Advanced Registered Nurse Practitioner, Physician Assistant, Licensed Clinical Social Worker or Psychologist be required to determine capacity for all others.

Regarding Regulatory Issues and Financing:

- .. That continuing education in EOL may be substituted for any of the current mandatory continuing education requirements (when other previously mandated requirements have been met in previous cycles);
- .. That the Legislature encourage the ongoing development of innovative EOL education programs for all health care providers;
- .. That the Legislature recommend that professional organizations develop strategies to promote and provide incentives for participation in EOL training and that these professional organizations incorporate EOL education in their on-going organizational activities;
- .. That the Legislature authorize the creation of a work group to review available curricula on EOL care and make recommendations through the respective Boards for curriculum materials to be incorporated into the basic curriculum of each school of medicine, nursing, social work, pharmacy, and other health related disciplines;
- .. That the Legislature create incentives for health and elder care providers and for publicly accessible media to encourage public dialogue about advance directives and EOL care;
- .. That the Legislature institute a proposal to encourage/recognize excellence in EOL care within health care facilities and other settings that care for seriously ill patients;
- .. That the Legislature amend F. S. Chapter 400. Part II and Chapter 395.1055(3) to include “good end-of-life care” as part of meeting federal mandates;
- .. That the Legislature add to F.S. Chapter 765.109 language to enhance protection for provider actions taken in accordance with an individual’s oral or written directives;
- .. That the Legislature provide for the portability of advance directives including a standard DNRO form that will be aligned with public information and public education;
- .. That the Legislature extend the Panel for the Study of End-of-Life Care until August 1, 2000 with funds appropriated for administrative and operational expenses;
- .. That the Legislature establish a working group to examine reimbursement methodologies for EOL care.

Introduction

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

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

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

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

In 1996, 152,697 Florida residents died. The death rate for women (both white and nonwhite) increased, while the death rate for white and nonwhite men declined. Of total deaths, 89% involved whites and 11% involved nonwhites. Heart disease was the leading cause of death (approximately one-third) and cancer was the second leading cause, accounting for almost one-fourth of the deaths.³ HIV was the third leading cause of death among nonwhites; the HIV death rate among nonwhite men was higher than the combined rates for white men and white and nonwhite women. Suicide was one of the top 5 causes of death for people aged 5 to 54; it is one of the top ten causes of death among 55-64 years olds. Among those 65 and older, the relative ranking of suicide deaths is supplanted by prominent disease-related causes.⁴

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

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

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

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

Patient satisfaction data suggests that hospice organizations have been better able to provide pain management to patients and that patients and families are more satisfied with their involvement in their care when in Hospice. Research indicates that the cost of hospice care in Florida results in an overall savings of Medicare dollars; a Lewin study reports that Medicare saves \$.52 for every dollar spent on hospice care.⁷ Unfortunately, many people are referred to Hospice too late to receive maximum benefit. Such late referrals result in unnecessary suffering for patients, as opportunities for quality care at the end of life are lost. Late referrals also result in significant financial costs to payers.⁸ Florida includes several of the hospital referral regions in which Medicare enrollees had the highest probabilities of spending some portion of the last 6 months of their lives in and Intensive Care Unit.⁹

In recent years, the proportion of Florida residents *without* health insurance coverage has increased to almost 19 percent (or more than 2.7 million people), making Florida one of the top ten states in percent not covered. Currently, 101 Florida physicians are certified by the American Academy of Hospice and Palliative Medicine, and 267 Florida nurses are certified by Hospice Nurses Association. Only 4 hospitals reported having palliative care units; however, more than 150 hospitals have contractual relationships with Hospices.¹⁰

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

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

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

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

⁸The Dartmouth Atlas of Health Care, 1998.

⁹ After standardizing for various demographic characteristics, the percent of Medicare enrollees spending one or more days in a coronary care or intensive care unit during the last 6 months of their lives ranged from less than 9% to more than 45%. Miami, St. Petersburg, Fort Lauderdale, and Jacksonville all had rates in excess of 40% (The Dartmouth Atlas of Health Care 1998: 86).

¹⁰ Personal communication from Samira K. Beckwith, Hope Hospice and Palliative Care.

Virtually all hospice patients and approximately half of nursing home residents are estimated to have advance directives which are noted on their medical records. Overall, approximately 18% of Florida residents have signed advance directives, a proportion higher than the national average; however, no systematic evidence of the percentage of hospitalized patients with advance directives noted on their medical records, nor of the percentage of patients with outside hospital DNR orders currently exists. We are unsure of how much influence advance directives or DNR orders have on the actual care received at the end-of-life.

As the organization of health care delivery has been reshaped and managed care relationships have become more common, consumer advocacy groups have encouraged individuals to become more assertive in health care decisions and to take steps to maintain control of their own care. The patient/physician relationship has increasingly emphasized patient autonomy and contractual obligations. This redefined relationship places an increasing burden on both consumers and health care professionals to learn and understand the legal, medical, ethical and financial issues involved in health care and undermines the trust between patient and physician, making “caring” difficult.

The physician/patient relationship exists within legal and ethical frameworks that must be continuously elaborated to effectively deal with the emerging questions with which science, technology, and the changing health care environment confront us. Cohorts of physicians who believe that their responsibility is to act in the best interests of their patients are increasingly faced with patients who ask that physicians’ care decisions be explained, justified, and subject to modification by the patient. These new relationships require enhanced skills of communication on the part of physicians and patients as well as regulatory safeguards that balance appropriate care (based on current medical research) with patient wishes.

Regulatory safeguards are designed to protect against the extremes—by placing a boundary at some point in the distribution of care practices and defining as problematic any behavior that exceeds that threshold. With health care practices, we must guard against extremes at both ends of the practice continuum—over- as well as under-utilization of care. Making regulations that are sufficiently responsive to ethical concerns, sufficiently flexible to provide adequate guidance under highly diverse conditions, and sufficiently sensitive to the cultural differences of patients and their families requires that all parties be willing to work together to forge solutions. It is within this setting that the Panel began its work.

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

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

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

Legislative Mandate. According to legislative mandate, the Panel's charge is to study the issues related to care provided at the end of life. Issues to be considered by the Panel include:

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

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

This is the Panel's Interim Report submitted to the Governor, the President of the Senate, and the Speaker of the House of Representatives. The Panel's next report is due on August 1st, 1999.

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

- Two persons representing hospice organizations and one consumer, appointed by the Florida Hospice Association (Samira K. Beckwith; Mary Labyak; Jack Gordon, alt. David Abrams);
- Three persons representing nursing homes and assisted living facilities; two appointed by the Florida Health Care Association and one by the Florida Association of Homes for the Aging (LuMarie Polivka-West; Dr. Howard Tuch, MD; Marshall Seiden, alt. Molly McKinstry);

- Three persons representing hospitals, one each appointed by the Florida Hospital Association, the Florida League of Health Systems, and the Association of Community Hospitals and Health Systems of Florida, Inc. (Dr. Susan White, alt. Bill Bell; Belita Moreton; Joan Fulbright);
- One person each appointed by the Florida Medical Association (Dr. Alvin Smith, MD), the Board of Medicine (Dr. Gary Winchester, MD, alt. Dr. Louis C. Murray, MD), the Board of Osteopathic Medicine (Dr. Robert Panzer, DO, alt. Dr. Archie H. McLean), The Florida Bar (Kenneth Rubin, alt. Mary Alice Ferrell), and the Florida Nurses Association (Cathy Emmett, alt. Dr. Georgie C. Labadie);
- One member appointed by the President of the Senate (The Honorable Ron Klein, alt. Kelly Skidmore);
- One member appointed by the Speaker of the House (The Honorable Dr. Robert Brooks, MD);
- One person representing the Commission on Aging with Dignity (Jim Towey, alt. Jackie Roberts);
- Two persons appointed by the Pepper Institute on Aging and Public Policy at FSU, including a member of the clergy (Dr. Marie E. Cowart, alt. Dr. Penny A. Ralston; Dr. Leo Sandon);
- One person representing the Health Quality Assurance Division of the Agency for Health Care Administration (Marshall E. Kelley, alt. Dr. Susan Acker);
- The Secretary of Elder Affairs, and one consumer representative appointed by the Secretary (Secretary E. Bentley Lipscomb¹¹, alt. June Noel¹²; Stan Godleski).

Dr. Bob Brooks was elected Chairperson of the Panel and E. Bentley Lipscomb was elected as Deputy Chairperson.¹³

¹¹ As Secretary for the Department of Elder Affairs, Mr. Lipscomb served as a member and as Deputy Chair of the Panel through December 1998. Thereafter he was replaced by the newly appointed Secretary, Dr. Gema Hernandez.

¹² June Noel, former Deputy Secretary of the Department of Elder Affairs served with the Panel through December 1998. She was replaced by the current Deputy Secretary, Carl Littlefield, who will act as alternate for Secretary Hernandez.

¹³ At the January 20th meeting, Dr. Marie Cowart was elected to be the new Deputy Chair of the Panel.

Membership.

Samira K. Beckwith

President and CEO, Hope Hospice and Palliative Care

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.

Dr. Bob Brooks, MD

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

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

Dr. Marie E. Cowart

Professor of Urban and Regional Planning, Florida State University

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

Cathy Emmett

Florida Nurses Association

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

Joan Fulbright

Senior Vice President, Association of Community Hospitals and Health Systems of Florida, Inc.

Ms. Fulbright has been with the Orlando Regional Healthcare system for 12 years, and was a founding member of the Orlando Regional Medical Center's Ethics Committee. Her current responsibilities include the development and management of all community-based social services for elders.

Stan Godleski

Consumer Advocate

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

Jack Gordon

Hospice Foundation of America

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

Marshall Kelley

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

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

The Honorable Ron Klein

Florida Senate

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

Mary Labyak

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

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

E. Bentley Lipscomb¹⁴

Former Secretary, Department of Elder Affairs

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

Belita Moreton

Florida League of Health Systems

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

Dr. Robert Panzer, DO

Florida Board of Osteopathic Medicine

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

LuMarie Polivka-West

*Senior Director of Policy and Quality
Assurance, Florida Health Care Association*

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

¹⁴ See footnote 11.

Kenneth S. Rubin***The Florida Bar***

Mr. Rubin is an attorney in private practice with an emphasis on elder law. He has held numerous positions and is presently an active member in the Elder Law Section of the Florida Bar and has been a member of the National Academy of Elder Law Attorneys since 1990. He is the founding director of the Broward County Alzheimer's Association.

Dr. Leo Sandon***Professor of Religion, Florida State University***

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

Marshall Seiden***CEO, Menorah Manor Inc.***

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

Dr. Alvin E. Smith, MD***Regional Oncology Center***

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

Jim Towey***Commission on Aging with Dignity***

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

Dr. Howard Tuch, MD***Director of Palliative Care Services, Genesis ElderCare***

Dr. Tuch is a board-certified internist and geriatrician. His current position is that of Director of Palliative Care Services for Genesis ElderCare, a geriatric health care company with over 350 centers nationwide. He is also director of the Palliative Care Program at Egret Cove nursing center in St. Petersburg. His clinical practice is limited to those in the final stages of terminal illness.

Dr. Susan V. White***Vice President/Quality Management, Florida Hospital Association***

Dr. White has over 20 years of experience in the health care field in administrative, managerial, and clinical roles. She has served as Associate Executive Director and Director of Nursing in a community hospital and worked on several quality management programs. She is on the faculty at the University of Phoenix-Florida Campus.

Dr. Gary Winchester, MD***Florida Board of Medicine***

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

Panel Activities

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

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

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

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

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

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

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

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

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

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

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

1. Concerns with advance directives:
 - Living Wills are not honored and wishes are not carried out at the end of life;
 - Documents are often confusing ;
 - Location and accessibility of documents when they are needed in a health emergency is problematic;
 - The lack of transportability of documents from different health care settings and across state lines is problematic;
 - The necessity of having a “terminal” illness diagnosis for a Do Not Resuscitate Order (DNRO) to be honored in certain settings and the necessity of having a “terminal” illness diagnosis for all other advance directives to be activated is problematic;
 - Circumstances under which advance directives are invoked are confusing;
 - People face difficulty in getting a terminal diagnosis even for very ill patients.

2. Concerns related to palliative care and pain management at end of life:
 - Concern over the lack of pain management and palliative care;
 - Concern over the lack of education for physicians and health care professionals in end of life care;
 - Misunderstanding and concern by physicians about the regulation of narcotics and subsequent hesitancy to prescribe pain medication;
 - Belief that pain should be considered as a 5th vital sign;
 - The need to include more hospice care in nursing homes.

3. Concerns with regulatory and financing barriers to care:
 - Concerns about conflicting regulations based on the location of end-of-life care;
 - Frustration with federal and state hospice limitations based on terminal illness time spans;
 - Concerns regarding the lack of financing by Medicaid and Medicare for palliative care services;
 - Need to address the end-of-life care needs of the uninsured;
 - Misunderstanding of the OBRA requirement to provide the “highest practicable level of care” not being translated as excellent end-of-life care;
 - Confusion over the guardianship, health surrogacy and proxy regulations for institutionalized residents no longer competent to make health care decisions.

4. Uncertainty regarding procedures for making end-of-life care decisions for the “unbefriended”, and the need for better health care guardianship and surrogacy.

Panel Goals and Recommendations

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

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

Pain Management/Palliative Care Working Group

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

The workgroup identified the following goals:

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

Recommendations:

1. All persons should have access to effective pain management and palliative care services. Dying has become a difficult grace within our modern and technologically driven health care system. The Florida legislature can promote meaningful change in the delivery of medical care at the end of life.
2. Adopt the World Health Organization’s definition of Palliative Care. Palliative care is defined according to the World Health Organization as: “the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best possible quality of life for patients and their families.”
3. Health care facilities, other organizations, and providers caring for people at the end of life should develop strategies to provide access to palliative care. Standards for pain management, management of other distressing clinical symptoms at the end-of-life, advance care planning, and systems to attend to emotional and spiritual needs should be in place or available in all settings which care for seriously ill patients.
4. The Agency for Health Care Administration and the Department of Elder Affairs should be directed to develop or adopt reasonable standards to monitor the implementation and effectiveness of pain and palliative care strategies.

Such standards may include:

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

[5 dissenting votes¹⁵]

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

Professional education.

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

¹⁵ Dissenters wanted the recommendation to read "Aggressive pain management to achieve acceptable comfort for people at the end of life . . ."

Public education

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

Advance Directives Working Group

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

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

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

Other items raised for discussion include:

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

The workgroup decided to focus on the following areas:

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

Recommendations:

1. Recommend that the Florida Legislature remove from F.S. 765 the requirement that a person be "terminally ill" before life-prolonging procedures can be withheld or withdrawn.
[1 dissenting vote¹⁶]
2. Recommend that the Legislature create a standardized and portable DNRO form that can be used in all patient settings. Create policy and procedures to implement the effective use of this form.
3. Recommend that the Legislature provide for "demonstration projects" by local communities in conjunction with the Department of Health as to mechanisms for implementation of pre-hospital DNROs.
4. If a legally executed advance directive has been executed, we recommend the requirement of the assessment and evaluation of one physician as to the patient's capacity. In the absence of a legally executed advance directives, we recommend two (2) physicians or one physician and one of the following professional licensed health care providers: ARNP (advanced registered nurse practitioner), PA (physician's assistant), Psychologist, LCSW (licensed clinical social worker) determine the patient's capacity.

¹⁶ The dissenter agreed that the current definition of terminal illness contained in the statute is seriously flawed, but would prefer rewriting the definition—perhaps expanding it to include some chronic conditions—and retaining the term in the statute.

Financial and Regulatory Working Group

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

Areas that the group identified as concerns include:

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

Recommendations:

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

With that outcome in mind, the Panel unanimously endorses the following goals:

- the right to refuse treatment and the patient’s right to make decisions about his or her care and his or her surrogate’s right to carry out the patient’s wishes when he or she is no longer capable of decision making.
- the right to die without aggressive curative treatment does not equal an obligation to die at any age or with any disability. This right is about supporting an individual’s right to make choices along the life continuum in the context of their values, their beliefs, and their situations.
- the realignment of existing financial resources to appropriately reimburse for palliative care.
- the right of all persons, regardless of insurance status, to be provided access to good end-of-life care.

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

1. that continuing education in end-of-life care may be substituted for any of the current mandatory continuing education requirements (when these requirements have been met in previous cycles) for professions that include but are not limited to, physicians, nurses, social workers, pharmacists, administrators of health care facilities, clergy and lawyers.
2. that the Legislature encourage the ongoing development of innovative end-of-life educational programs for all health care providers.
3. that the Legislature recommend that professional organizations representing the aforementioned groups develop strategies to promote and provide incentives for participation in end-of-life training and that these professional organizations incorporate end-of-life education in their on-going organizational activities.
4. that the Legislature authorize the creation of a work group comprised of but not limited to a representative from the Board of Medicine, the Board of Osteopathic Medicine, the Board of Nursing, the Board of Pharmacy, the Board of Nursing Home Administrators, one School of Medicine, one School of Social Work, and Chairs of the four (4) Florida medical schools' curriculum committees, to review available curricula on end-of-life care and make recommendations through the respective Boards for curriculum materials to be incorporated into the basic curriculum of each school of medicine, nursing, social work, pharmacy, and other health related disciplines.
5. that the Legislature create incentives for health and elder care providers and for publicly accessible media such as the press and public radio and television designed to encourage public dialogue about advance directives and end-of-life care options. Incentives might take the form of citation in annual ratings for providers, and private funding for public radio and television productions that reflect the multicultural diversity in our communities.
6. that the Legislature institute a legislative proposal that encourages excellence in end-of-life care. Criteria of excellence should include but not be limited to: 1) a mechanism for effective conflict resolution regarding end-of-life decisions (e.g. an active ethics committee); 2) a facility-based palliative care program ; 3) and/or a formal affiliation with a hospice organization. Such conditions should define eligibility for awards recognizing excellence in health care facilities (e.g. a Gold Seal award for nursing homes).
7. that the Legislature insert into F.S. Chapter 400, part II, and Chapter 395.1055(3), the inclusion of "good end-of-life care" as evidenced by a system to improve pain and symptom management, provide advanced care planning, and psycho/social support as a part of meeting the OBRA mandate of providing the "highest practicable level of care."
8. that the Legislature add to F.S. Chapter 765.109, language to enhance protection for provider actions taken in accordance with the individual's oral or written advance directive statements that have been expressed by a competent informed and un-coerced adult and appropriately activated; and that such language be added to the respective statutory provisions governing health care providers and health care entities.

9. that the Legislature provide for the portability of advance directives including a standard DNRO form that will be aligned with complementary public information and public education; establish a work group under the auspices of the end-of-life advisory panel to develop a standard DNRO form that will be accepted and used among all providers in the continuum of care. The advisory group will be comprised of the involved providers and a representative of the Elder Law Section of the Florida Bar.

[1 dissenting vote¹⁷]

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

¹⁷ Disagreement over the advisability of any type of form.

Appendices

1. CS/CS/HB 3387
2. List of Panel Members and Alternates
3. List of Advisory Board
4. Minutes of Panel and Working Group Meetings

FOR FURTHER INFORMATION CONTACT:

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