

# NETWORK NEWS

## The newsletter of the Florida Bioethics Network

a Health Service Group of the Florida Hospital Association - P.O. Box 531107 - Orlando, Florida 32853-1107 - 407-841-6230

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98-3

### President's Message

#### Patient Rights and Faulty Law: The Problem with Florida Statutes

Ken Goodman, PhD  
University of Miami Forum for Bioethics

No issue commands the attention, consumes the time and occupies the efforts of ethics committees more than death — or, more properly, the end of life. This is particularly so in Florida and other populous states with large elder populations. It is therefore a source of interest if not amazement that there remains so much confusion and misunderstanding surrounding patient rights at the end of life. One might have thought that with all our experience, we would have resolved a number of key points. Take for instance the following trick question:

*If an informed, competent, uncoerced adult wants to refuse life-sustaining treatment, how many physicians must certify that the patient is terminally ill before the refusal can be honored?*

- (A) 1
- (B) 2
- (C) more than 2
- (D) none of the above

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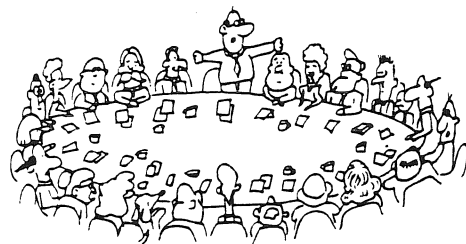
### Save the Dates: October 21-23, 1998

#### Eighth Annual Florida Bioethics Network Conference

#### Current Challenges in Healthcare Ethics

Make your plans now to attend this important conference and networking opportunity. Speakers and participants representing ethics committees from all parts of Florida will attend to discuss issues such as: Empowering the Patient/Family/Surrogate; Recommendations for Revisions of Chapter 765, and Qualifications for Bioethics Case Consultants. The program will conclude with a panel discussion on Autonomy and Dependency by leaders in the field of aging. Panel members include: Larry Polivka, Ph.D., Director of the Florida Policy Exchange Center on Aging at USF, who has presented at numerous national conferences including the American Society on Aging and the Gerontological Society on Aging; Bruce Robinson, MD, Chief of Geriatric Medicine at USF, who also has presented at many national conferences and is a Fellow in the American Geriatrics Society; and June Noel, Asst. Director of the Florida Department of Elder Affairs and leader of the Florida Task Force on Ethics and Aging.

We hope to see many of you at the Orlando Airport Marriott in October. Call 407-841-6230 for more information.



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Network News welcomes letters, comments and articles for inclusion. Please send any correspondence to dmphotos@gte.net or Cathy Emmett, Hospice of Southwest Florida, 5955 Rand Blvd., Sarasota, FL 34238, Fax: 941-921-5813.

**Patient Rights and Faulty Law***continued from page 1*

The answer is of course (D). Informed, competent, uncoerced adults can and may refuse *any* treatment, including hydration and nutrition — from breakfast to brain surgery — without being terminally ill and without convening a panel of physicians. And living wills are a way to do this in advance of incapacity, but you wouldn't be able to tell this at a number of hospitals and nursing homes around the state.

*Why the misunderstanding?* It is difficult to say exactly why, although one hypothesis is that Florida law seems to say so, at least in the case of living wills. Chapter 765 of Florida Statutes (on "Health Care Advance Directives," which should be required reading for all ethics committees) simultaneously recognizes patients' right to refuse treatment and requires that two physicians determine that a patient is terminally ill before a living will to limit treatment can be honored.

*This is an ethical mistake.* There is no reason to submit treatment refusals to a vote by physicians in cases in which patients meet the criteria for valid refusal, namely that they are adequately informed, they are not being forced or tricked by anyone, and they are competent (or were when they executed the advance directive).

**The "two-physician myth"**

Worse, Chapter 765 includes a sample living will that repeats the two-physician requirement. Despite that the living will is identified as an exemplar, and that there is absolutely no requirement that the document be used, it is an unhappy fact that this living will is used by numerous hospitals, attorneys and others who supply advance directives. The "Five Wishes Living Will" published by the Florida Commission on Aging With Dignity (which despite its name is a private and not an official entity), likewise mistakenly enshrines the two-physician myth.

These documents imply that patients lose their right to refuse treatment after they become incompetent or unable to articulate their wishes. As we say in ethics, this is a hoot.

In countless cases, the very reason for a living will in the first place is to refuse in advance — and while competent — at least some and maybe all life-prolonging treatments. One does not need to appeal to terminal illness to exercise the right to refuse treatment. (To be sure, if a patient *wanted* to stipulate a terminal condition obtained before life-prolonging treatments could be halted, this would be within his or her rights.)

Moreover, there is ample case law — not least the U.S. Supreme Court's Cruzan decision and the Florida Supreme Court's 1990 Browning ruling — that underscores the right of patients, including those no longer enjoying the capacity to make decisions, to refuse treatment. There seems to be no evidence that hewing to the two-physician criterion reduces liability. There is plenty of evidence that it reduces patient rights.

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## Patient Rights and Faulty Laws

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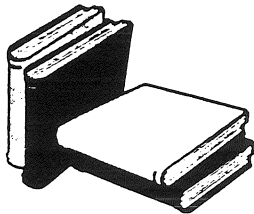
### Opportunities for progress

These and other challenges presented by Florida law were aired and debated in May at an outstanding conference in Gainesville hosted by the University of Florida's program in Medical Ethics, Law and the Humanities. Health professionals and officials from around the state grappled with ways to improve the law — and hence ways to improve Floridians' ability to exercise basic rights.

Similarly, the Florida Legislature this year created a "Panel for the Study of End-of-Life Care." Based at Florida State University in Tallahassee, the panel will have an opportunity to address these challenges and perhaps make recommendations to policymakers. Florida Bioethics Network members and others who have struggled to balance patient rights and faulty law should consider sharing their experience and concerns with the panel.

At the end of the day and at the end of life, misunderstanding and a lack of education remain the greatest obstacles to respecting patient wishes. Members of ethics committees, administrators and others should view this as an opportunity to develop high-quality programs to train patients, families and health professionals about end-of-life challenges — and about the foundations of patient rights.

## References of Interest



*Submitted by Kathleen Weldon, Senior Vice President of Patient Care Services, Wuesthoff Hospital, Rockledge*

Comfort Care Only for Patient? A Question of Proof. *Malpractice Focus, Physician Financial News*, March 15, 1998, pg. 47, David Rubsamen, MD, LLB

The Latest Malpractice Risk: Ignoring a Patient's Right to Die with Dignity. *Medical Economics*, Feb. 23, 1998, pp 226-241

A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients, *JAMA*, Nov. 22-29, 1995, Vol. 274, No. 20

The Health Care Ethics Committee Experience: Selected Readings from HEC Forum, ed. By Stuart F. Spicker, Kreiger Publishing Co., Malabar, FL 1998

## Response to the Case of Mrs. H

*Submitted by Cathy Emmett, ARNP, CS  
Hospice of Southwest Florida*

In the last issue, Dr. Kathryn Koch submitted a case regarding a Vietnamese woman with lung cancer. The daughters, who appear to be very devoted to their mother, are unified in their opinion that it would be devastating for their mother to be informed of her diagnosis. According to them, she holds strong cultural imprinting which makes her personally responsible for any illness. They note that she still cries every night in grief and guilt over the failure of her marriage (which had ended in divorce eight years ago). The issues this case raise are very interesting and I believe will become more prevalent as we find individuals and families from other countries and cultures faced with end of life decisions in the United States.

Our country places an extremely high emphasis on an individual's right to make decisions. So valued is that right, that an individual can make directives so that their wishes can be followed even if they are unable to participate in the decision making process; thus our advance directives are recognized in hospitals throughout the United States. In ethics committees that I have had the opportunity to participate with, the first question we always ask is, "Do we know what the patient wants done, or would have wanted done?" If the patient is competent, as Mrs. H appears to be, often the Bioethics Committee feels there is no further discussion needed - simply tell the patient the facts and let him/her make an informed decision. In many cultures however, this overriding value of individual autonomy is not the most important value. Allegiance to family, religion, harmony with nature, may be much higher values that need to be attended to.

If the hospital's lawyers were consulted, they might indicate that from strict interpretation of the law, the healthcare providers should ignore this competent patient's daughters' wishes and give the patient the information and let her make the decision. Most members of a bioethics committee would, I suspect, want to explore other options to be able to provide good care for this woman, while honoring her cultural beliefs. And what exactly are these beliefs? I myself have had no direct experience with the Vietnamese culture. While the daughters appear to be very devoted to their mother, if they were born and/or raised in the United States, do they really understand their mother's perspective? It might be helpful to see if there is someone from that cultural background and age cohort who could verify the belief and value system that the daughters have described.

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