

MINUTES OF THE HOUSE KANSAS FUTURES COMMITTEE

The meeting was called to order by Chairman Carlos Mayans at 1:30 p.m. on February 20, 2001 in Room 526-S of the State Capitol.

All members were present except: Representative Karen DiVita - excused
Representative Mike O'Neal - excused

Committee staff present: April Holman, Legislative Research Department
Lynne Holt, Legislative Research Department
Amy Kramer, Legislative Research Department
Mary Best, Acting Committee Secretary

Conferees appearing before the committee:
Donna Bales, Director, The Kansas Life Project, Wichita

Others attending: See attached list.

The Kansas Life Project

Donna Bales described the organizational coalition of health care provider organizations who work together for excellence in end-of-life care for all Kansans. She distributed a brochure, entitled "*A Design for Change*" (published by the Project) which is an overview of its research and study, and the initiatives and goals the Project has undertaken to help all Kansans live with dignity, comfort and peace at end-of-life. Also distributed were papers on "*Advance Care Planning*", "*Principles of Pain Management*", and "*Principles of Palliative Care*" (see Attachments 1, 2, 3, and 4).

Ms. Bales also described a wall chart, prepared by the Life Project, entitled "*End of Life - Kansans Deserve Excellent Care*". It is posted in physicians exam rooms, libraries, pharmacies, and senior centers to point Kansans to the idea they have a role in their health care at the end-of-life. She noted that end-of-life information may be obtained through their toll free telephone number (1-800-202-5433) or at the computer web site <http://www.LifeProject.org>

Ms. Bales noted the healthcare system has been created to throw certain procedures and techniques in place but not so much to listen to patient wishes. She drew attention to the changing numbers of the elderly demographics and pointed out "there are 25 million at-home caregivers providing 80% of care to chronically ill Americans. End-of-life planning is the last thing people want to talk about."

She stated there is a disincentive for offering good end-of-life care. Physicians can receive no reimbursement for sitting down and spending time with the family to talk about the choices that need to be made, the options there may be, or the issues within the family. Outside of hospice care, there is no reimbursement for that kind of time.

Also, there is a health care system in place that is not prepared to offer palliative care (which the Life Project endorses); plus growing numbers of people living with disabilities and serious illnesses that are needing care for longer periods of time; and fewer and older people available to serve as caregivers. This means a crisis is looming. She asked with what we know, what do we do now and in the future to make a difference; then suggested three areas that need to be addressed if we are going to offer good end-of-life care:

- (1) Professional Education. Action has begun in this regard as the Joint Commission that accredits most hospitals this year established standards on pain management; the Journal of the American Medical Association now includes periodic articles on end-of-life care; the National Institute for Health has increased funding for end-of-life issues; and HCFA has been asked to re-visit Hospice criteria. The Kansas Life Project has created a Pain Protocol group to develop pain management guidelines.
- (2) Public Policy to focus on examining advance care planning. Issues surrounding guardianship and

CONTINUATION SHEET

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surrogacy create problems, which includes physicians and pharmacists liability with respect to pain management.

- (3) Legislators were encouraged to make public statements and conduct discussions to encourage end-of-life planning.
- (4) Ms. Bales noted that the Board of Healing Arts, the Pharmacy Board, and the Board of Nursing have no way officially of collaboration. She stated the Project had examined all of the statutes and regulations and found there is nothing in them to prevent good end-of-life care. She asked legislators to hold these boards, as well as the licensing boards, accountable for end-of-life care and pain management.
- (5) Address the nursing shortage by considering mechanisms to assure adequate nursing services. Two states are introducing scholarships for nursing.
- (6) Expect good pain management; listen to citizens concerns.
- (7) Encourage development of palliative care teams and support reimbursement for these services.
- (8) Address caregivers issues; support funding for them.
- (9) Follow national developments, such as the new Improvements and Protection Act.
- (10) Understand the costs to employers when their employees are also caregivers.
- (11) Support the Life Project.
- (12) Offer spiritual support and social interactions for end-of-life.

Vice-Chairman Bethell asked about the intent of the new federal "Pain Relief Promotion Act". Ms. Bales explained that the bill includes provisions that the Drug Enforcement Agency (DEA) will judge the physician's intent when it is questioned that the prescribed treatment seemed to hasten death. DEA testified that it is not trained to make these decisions. The Vice-Chairman asked her to also address the issue of the final drug dose that eliminates pain but slows respiration to the point of death. Ms. Bales responded there is a state of terminal sedation. The Kansas law is considered to be a good pain management law and it provides that physicians may prescribe good pain management. Asked what are the major barriers to pain management, Ms. Bales listed fear of dying, addiction, and being afraid of drugs.

Representative Miller asked if the subject of assisted suicide had been discussed by the Life Project. Ms. Bales noted it had been brought up but the Life Project does not take a stand on it. The Association of Hospices does not support physician-assisted suicide.

The next meeting is scheduled for February 28, 2001.