

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.

CONTINUATION SHEET

MINUTES OF THE HOUSE KANSAS FUTURES COMMITTEE at 1:30 p.m. on February 20, 2001 in Room 526-S of the State Capitol.

- (2) Public Policy to focus on examining advance care planning. Issues surrounding guardianship and 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.

KANSAS FUTURES COMMITTEE
GUEST LIST
FEBRUARY 20, 2001

[PLEASE PRINT YOUR NAME]

[REPRESENTING]

Randolph D. Scott, LBSW

Washburn University

Jim Allen

AKH

Elaine Schwartz

KDOA

Maddy Stansberry

South Middle School

Amy Hoppock

Salina South Middle School

Jessica Coleman

Salina South Middle School

Kelsey Lilly

Salina South Middle School

Kendra Ramsey

Salina South Middle School

anne Drake

University of Kansas

Elizabeth Nichole McClelland

University of Kansas

Sheila Walker

University of Kansas

Tom Bruno

AKH

TOM SIFE

KS HOA Assoc.

Margaret Zillman

SRS/NCP

LISA CHRISCO

SRS/HCP



A Design for Change

END OF LIFE CARE ISSUES IN KANSAS

When we enter this world, we are surrounded by love, comfort and care. Do we not deserve the same when we leave?

Committed to that end, the Kansas LIFE Project was born. Living Initiatives For End-of-Life Care (LIFE) is a coalition of partnered organizations working together for quality care for all Kansans at the end of life.

The Project began when a diverse group of health care provider organizations, associations, medical boards, advocacy groups and state agencies were convened in February 1998, by the Association of Kansas Hospices. The participants quickly reached a consensus to work together for excellence in end-of-life care for all Kansans.

Following that initial meeting, a growing

group of participants representing the many stakeholders on these issues began to identify the barriers to providing quality end-of-life care for Kansans. The LIFE Project formed three task groups—public policy, professional education and public engagement.

A Design for Change is a series of brief papers designed to inform and engage Kansas leaders in improving end-of-life care for all Kansans. This issue of *A Design for Change* addresses three questions:

- Why should Kansas public policy leaders be interested in improved end-of-life care?
- What are the LIFE Project

strategies?

- What may Kansans expect?

"It is not easy to talk about death and dying with our loved ones. That is why this initiative is so important. It creates the opportunities in our communities to have these discussions within a supportive environment that can provide education about our choices and direct us as families to those professionals who can help. Hopefully those discussions can begin before we are confronted with the immediacy of a loved one who is in the final passages of life."

—Senator Sandy Praeger

The LIFE Project is located at the Association of Kansas Hospices
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Thank You to Sylvia Root, Topeka, for sharing her story

HOUSE KANSAS FUTURES

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Attachment 1



Advance Care Planning

For the first time in human history there are many choices about when, where, and how a person will die. These choices are the result of dramatic changes in medical science and technology. Some choices are complex and stressful for those who must make them. Frequently, the person involved is no longer able to choose and someone else must step in.

Most people die in hospitals or nursing homes. Very often, death is a result of a decision to stop or not to start a treatment or procedure. Usually, family members and friends work with doctors and nurses to decide what is best for the patient. In the past, we believed that all efforts to prolong life and restore function were good. Today, it is sometimes hard to know whether we are prolonging life, or just making the dying last longer. The decisions are important and sometimes very difficult, especially when not everyone involved can agree.

Advance care planning is a communication process through which we engage our family and friends, physicians, clergy and others in planning for future health care needs. The process involves thinking and talking about goals, values, religious preferences, and comfort issues with people who are important to us or who may be involved in decisions about our health care. Advance care planning is a good idea for people of all ages.

Principles of advance care planning

1. Advance planning reflects your wishes. It ...
 - reflects your right to make your own choices and decisions;
 - helps you develop a personal understanding about pain, artificial life support, hospitalization and other health care issues;
 - allows you to deal with these hard questions in a time and place when you are comfortable and not feeling pressured;
 - assures that your wishes for treatment will not be overlooked or neglected; and
 - helps you tell your physician, family and friends about your goals, likes, dislikes, and choices.

2. Advance planning involves the people who are important in your life. It ...
 - helps families know that they are following your wishes;
 - helps physicians and the health care team provide care that matches your values and wishes; and
 - identifies someone you trust to make decisions for you if a time comes when you are no longer able to make decisions for yourself.

3. Advance planning works for you. You may ...
- name someone you trust to make decisions for you when you are no longer able, by using a document called Durable Power of Attorney for Health Care Decisions;
 - write other formal advance directives, called living wills or treatment directives, in which you give specific instructions about your wishes;
 - make informal advance directives in which you clarify your preferences for end of life care;
 - change your mind about what you want. You can change your advance directives if your health changes or if your ideas about health care change;
 - continue making your own health care decisions as long as you are able;
 - protect yourself from receiving treatments that you do not want; and
 - protect the people who care for you.



Principles of Pain Management

Pain is best defined as defined as “whatever the experiencing person says it is, existing whenever he says it does.” (Margo McCafferty, *Nursing Practice Theories*, 1968) It is an inherently subjective experience that produces significant changes in many aspects of people’s lives. The proper management of pain must be a major priority for all health care providers for all patients. The Living Initiatives for End-of-Life Care endorses the following Precepts of Pain Management.

- All patients have the right to have their pain relieved to the greatest extent possible.
 - The patient’s age, gender, race or ethnic background, insurance or reimbursement status, religious beliefs, lifestyle choices, stage of illness, underlying diagnoses, and/or history of substance abuse do not change this right.
 - Some groups, including children, the elderly, the uninsured or underinsured, the mentally or physically disabled, and those with a history of addictions need to have special care to be sure that their pain is well treated.
- A comprehensive pain assessment should be done at the initiation of treatment, and pain should be assessed regularly at each contact with the health care system after that.
 - Pain should be considered the fifth vital sign.
 - Pain assessment should be comprehensive, including assessment of not only pain intensity and quality, but also side effects, mood, and the impact pain has had on the patient and his/her multiple roles in life, the patient’s family, and others close to the patient.
 - The patient’s spiritual life is a very important contributor to the ability to cope with pain, and should be assessed and supported in a manner consistent with the patient’s wishes.
- Given the widespread impact of pain in a patient’s life, a multidisciplinary team approach is optimal and should be utilized whenever possible.
- Because pain is an inherently subjective experience, the patient’s report of pain is the “gold standard” upon which all interventions are based.
- The ultimate goal of treatment is to alleviate as much of the patient’s pain as possible.
 - In some cases, it may not be possible to alleviate all the patient’s pain; if this is the case, the goal should be to reduce the pain to the level specified by the patient as representing his/her personal goal.
 - To achieve optimal pain relief, careful attention must be paid to side effects and their treatment; the goal is to achieve maximal pain relief with minimal or no side effects.
- Research indicates that most patients can achieve optimal pain relief with simple, cost-effective modes of treatment. Therefore, clinicians should pursue such modes of

treatment to their maximal benefit before pursuing more invasive and costly alternatives.

- Pain management should continue throughout the course of the patient's illness, even if the patient becomes unresponsive near the end of life.
- At the end of life, management of pain and other symptoms is vitally important to insure that the patient dies as peacefully as possible.
- If all other reasonable means have failed, sedation of the patient until the time of death as a means of controlling symptoms is acceptable.
- Physician-assisted suicide and euthanasia are not acceptable alternatives to the optimal management of pain.



Principles of Palliative Care

Respecting Patient Goals, Preferences and Choices

Palliative Care:

- Is an approach to care that is foremost patient-centered and addresses patient needs within the context of family and community.
- Recognizes that the family constellation is defined by the patient and encourages family involvement in planning and providing care to the extent the patient desires.
- Identifies and honors the preferences of the patient and family through careful attention to their values, goals and priorities, as well as their cultural and spiritual perspectives.
- Assists patients in establishing goals of care by facilitating their understanding of their diagnosis and prognosis, clarifying priorities, promoting informed choices and providing an opportunity for negotiating a care plan with providers.
- Strives to meet patients' preferences about care settings, living situations and services, recognizing the uniqueness of these preferences and the barriers to accomplishing them.
- Encourages advance care planning, including advance directives, through ongoing dialogue among providers, patient and family.
- Recognizes the potential for conflicts among patient, family, providers and payors, and develops processes to work toward resolution.

Comprehensive Caring

Palliative Care:

- Appreciates that dying, while a normal process, is a critical period in the life of the patient and family, and responds aggressively to the associated human suffering while acknowledging the potential for personal growth.
- Places a high priority on physical comfort and functional capacity, including, but not limited to: expert management of pain and other symptoms, diagnosis and treatment of psychological distress and assistance in remaining as independent as possible or desired.
- Provides physical, psychological, social and spiritual support to help the patient and family adapt to the anticipated decline associated with advanced, progressive, incurable disease.
- Alleviates isolation through a commitment to non-abandonment, ongoing communication and sustaining relationships.
- Assists with issues of life review, life completion and life closure.
- Extends support beyond the lifespan of the patient to assist the family in their bereavement.

Utilizing the Strengths of Interdisciplinary Resources

Palliative Care:

- Requires an interdisciplinary approach drawing on the expertise of, among others, physicians, nurses, psychologists, pharmacists, pastoral caregivers, social workers, ancillary staff, volunteers and family members to address the multidimensional aspects of care.
- Includes a clearly identified, accessible and accountable individual or team responsible for coordinating care to assure that changing needs and goals are met and to facilitate communication and continuity of care.

- Incorporates the full array of inter-institutional and community resources (hospitals, home care, hospice, long-term care, adult day services) and promotes a seamless transition between institutions/settings and services.
- Requires knowledgeable, skilled and experienced clinicians, who are provided the opportunity for ongoing education, professional support and development.

Acknowledging and Addressing Caregiver Concerns

Palliative Care:

- Appreciates the substantial physical, emotional and economic demands placed on families caring for someone at home, as they attempt to fulfill caregiving responsibilities and meet their own personal needs.
- Provides concrete supportive services to caregivers such as respite, round-the-clock availability of expert advice and support by telephone, grief counseling, personal care assistance and referral to community resources.
- Anticipates that some family caregivers may be at high risk for fatigue, physical illness and emotional distress, and considers the special needs of these caregivers in planning and delivering services.
- Recognizes and addresses the economic costs of caregiving, including loss of income and non-reimbursable expenses.

Building Systems and Mechanisms of Support

Palliative Care:

- Requires an environment that supports innovation, research, education and dissemination of best practices and models of care.
- Needs an infrastructure that promotes the philosophy and practice of palliative care.
- Relies on the formulation of responsible policies and regulations by institutions and by state and federal governments.
- Promotes equitable and timely access to the full array of interdisciplinary services necessary to meet the multidimensional needs of patients and caregivers.
- Demands ongoing evaluation, including the development of research-based standards, guidelines and outcome measures.
- Assures that mechanisms are in place at all levels (e.g., systems, direct care services) to guarantee accountability in provision of care.
- Requires appropriate financing, including the development of new methods of reimbursement within the context of a changing health care financing system.

Adapted and adopted from the Last Acts Campaign