Approved: January 18, 2006
Date

MINUTES OF THE HOUSE HEALTH AND HUMAN SERVICES COMMITTEE

The meeting was called to order by Chairman Jim Morrison at 1:30 P.M. on January 17, 2006, in Room 526-S of the Capitol.

All members were present except Representatives Landwehr and Kilpatrick.

Committee staff present:
Melissa Calderwood, Kansas Legislative Research Department
Mary Galligan, Kansas Legislative Research Department
Renae Jefferies, Revisor of Statutes' Office
Gary Deeter, Committee Secretary

Conferees appearing before the committee:
Donna Bales, President and CEO, Life Project
Robert Twillman, Ph.D., LIFE Project Pain Management Task Group, University of Kansas Medical Center
John G. Carney, Vice President, Aging and End-of-Life Center for Practical Bioethics

Others attending:
See attached list.

The Minutes for 1-10-2006 were approved. (Motion, Representative Bethell; second, Representative Kiegerl.

Donna Bales, President and CEO, Life Project, introduced the topic, "Critical Issues in End-of-Life Care," stating that her organization represents many collaborative organizations across the state (Attachment 1). She said the goal of the Life Project is to assure that Kansans who face the end of life will be able to do so with dignity, comfort and peace. She stated that the following presenters would provide perspective on end-of-life issues.

Robert Twillman, Ph.D., LIFE Project Pain Management Task Group, University of Kansas Medical Center, stated that chronic pain and drug addiction are major public health issues; he outlined the state's pain policies, noting both positive and negative aspects of these policies and commenting that Kansas was one of only 4 states to receive a high grade on its pain policies (Attachment 2). However, he stated that these policies were not reflected in statute or regulations. He commented that two statutes (Prevention of Assisted Suicide Act and the Medical Practices Act) perpetuate the incorrect belief that opioids hasten death.

Dr. Twillman suggested four ways to improve pain management: develop practice guidelines, monitor quality improvement, educate health-care providers and patients, and adopt better policies and standards.

He recommended the standards expressed in the Controlled Substances Act, further recommending that Medicare and Medicaid drug coverage be as unrestricted as possible.

John G. Carney, Vice President, Aging and End-of-Life Center for Practical Bioethics, provided information on advance care planning and artificial nutrition and hydration (Attachment 3). He reviewed the current status of advance health-care directives in Kansas: the living will statute (**K.S.A. 65-28, 101**, the power of attorney statute (**K.S.A. 58.625-632**), the pre-hospital Do Not Resuscitate (DNR) statute (**K.S.A. 65.4941**), and the guardianship provision on withholding and withdrawing hydration and nutrition (**K.S.A. 59-3075(e)(7)(C)** **(HB 2307)**.

Regarding the living will statute, he said it serves as a record of the patient's wishes and provides a guide for families, although in practice most Americans do not prepare one, or, when it is needed, it is not available. Also he noted that as dementia becomes more prevalent, what was assumed to be a static decision becomes a drawn-out process.

Mr. Carney said the durable power of attorney for health care (DPOA) is a legal document that appoints a particular person to make medical decisions for someone who is incapacitated, a companion document to a living will, but often ineffective in emergency situations. Mr. Carney said the DNR is valuable to help family members avoid anguishing decisions, but again are difficult to honor in emergency situations, noting that DNR specifically applies only to heart/lung failure. He cited a recent study by the federal Center for Disease Control (2004) that for the first time in American history, chronic illnesses became the leading cause of death

Regarding guardian issues, Mr. Carney said the Kansas statutes were comprehensively updated in 2002, with limits and exceptions clearly spelled out. He commented on recent trends, noting that North Carolina and Vermont allow digital repositories—web sites where advanced directives can be posted. Some states are combining living wills and DPOAs into one document, and others are providing an alternative to DNRs, a document called POLST (physician orders for life-sustaining treatment), which gives more latitude for life-sustaining decisions.

A monograph was also distributed to the committee: "Pain Management: Promising Practices and Frightening Fragmentation," (Attachment 4).

Conferees responded to members' questions: Mr. Carney said that to date the Kansas Medical Society has not acted to endorse any of the trends, although the American Medical Society had endorsed POLST. To another question, he said that there are statutory limits on guardianship that are not applicable to a DPOA. Mr. Twillman distinguished between drug dependence and drug addiction, saying the former is solely physical, but the latter includes psychological factors.

The Chair thanked the conferees and opened the floor for bill requests and/or introductions. Representative Goico requested a bill that would allow a person who receives training through an internet course to take a licensure test. The request was approved.

Representative Bethell requested introduction of two bills and one resolution: a pain patient's bill of rights; a requirement that applications for Medicare or Medicaid include advance directives and living wills; and a resolution that private insurance companies include an advance directive and a living will as a part of an insurance policy presentation. The request was approved.

Representative Kiegerl requested a resolution concerning the dangers of cardiovascular disease for women. The request was approved.

The meeting was adjourned at 2:46 p.m. The next meeting is scheduled for Wednesday, January 18, 2006.

HOUSE HEALTH AND HUMAN SERVICES COMMITTEE
GUEST LIST

DATE: JANUARY 17 2006

NAME	REPRESENTING
Sarah Tidwell	KSNA
Robert Twillman	LIFE Project
JOHN CARNEY	LIFE PROJECT
Megan Loomis	page of Mike Kiegerl
Brianna Hand	
Debbie Lowery	
Cameron Vande Velde	page for Mike Kiegerl
Reed Vande Velde	page for Mike Kiegerl
Erlinda Hand	
Bobby Hand	
ROBERT HAND	
JOANNA DE LEENER	
Tom Bruno	The Life Project
Josie Torrez	SILCK
Sharon Joseph	KS ADAPT
Kevin Siek	TILRC
Janet Neff	KDHE-Cancer Program
Estelle Montgomery	Hein Law Firm
Cooper Martin	Rep. Phelps

HOUSE HEALTH AND HUMAN SERVICES COMMITTEE
GUEST LIST

DATE: Jan 17, 2006

Page 2

NAME	REPRESENTING
Michelle Peterson	Capitol Strategies
Marcy Quiason	Rep. Barbra Ballard
Jamie Epstein	Rep. Sue Storm
Cynthia Smith	SCL Health System
Brent Wistrom	Wichita Eagle

Attachment 1
HHS 1-17-06

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

Critical Issues in End-of-Life Care

Donna Bales
President and CEO
Kansas LIFE Project

L I F E
PROJECT

Living Initiatives For End-Of-Life Care
Helping Kansans with advance, chronic and terminal illnesses live with dignity, comfort and peace

January 17, 2006

Living near life's end is a reality that every one of us will face. It is the hope of the LIFE Project that this time in the life of every Kansan will be filled with dignity, comfort, peace and meaning. We know that this is only possible if Kansans' needs are identified and addressed and if public policy, professional education and public engagement all support Kansans and their families.

Near life's end, citizens deal with issues related to making important healthcare choices, creating and living meaningful days in life's last chapter and attending to personal and family concerns.

During 2004, the LIFE Project held a number of Town Hall meetings – all across Kansas—to listen to and learn from Kansans about their hopes and wishes about how they live as they near the end of life. The issues that they identified are the key focus of the work of the LIFE Project as we serve as the advocates for these citizens.

Kansans tell us that they want:

Good pain and symptom management
To have their wishes in care known and honored
To be told the truth about their medical conditions and illness t
To be treated respect
To not be abandoned
To avoid financial devastation
To not be a burden to their families

The LIFE Monograph titled, "LIFE Matters: Achieving Excellence in Care for Kansans with Advanced Chronic and Terminal Illnesses" describes our learning and outlines the six movements that we believe are important to address the needs and wishes of Kansans.

In addressing these needs, the public policy spotlight focuses on issues related to pain management; advance care planning and the administering of artificial nutrition and hydration. It is these three critical issues that we will address today.

Our latest monograph, "Critical Issues in End-of-Life Care" was created to provide information, for you our policy leaders, as you consider these important needs for these most vulnerable citizens.

Thank you for the opportunity to share with you today and to work with you as partners in seeking to protect the needs of Kansans and enable quality of life –even at life's end.

Donna Bales
President and CEO

LIFE Project Foundation ♦ 1901 University ♦ Wichita, KS 67213-3325
Phone: 316-263-6380 ♦ Fax: 316-263-6542 ♦ Email: life@LIFEProject.org ♦ Website: www.LIFEProject.org
Statewide Consumer Toll-Free HelpLine: 888-202-LIFE (5433) ♦ Pain Management HotLine: 913-588-3692
The LIFE Project Foundation is a 501(c)3 non-profit organization

Attachment 2
HHS 1-17-06

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

Pain Management: Policy Considerations for 2006

Robert Twillman, Ph.D.
University of Kansas Medical Center
LIFE Project Pain Management Task Group

Why it's important

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

"We all must die. But that I can save him from days of torture, that is what I feel as my great and ever new privilege. Pain is a more terrible lord of mankind than even death itself."

Albert Schweitzer

Pain is a Major Public Health Issue

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

- Chronic pain affects 35-50% of adult Americans (50-70 million people)
- 80% of patients present for health care because of pain
- Over 40% of acute care patients report poor pain control
- 50% of dying patients report moderate to severe pain
- Unrelieved pain costs our economy over $100 billion each year

Drug Addiction is a Major Public Health Issue

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

- 2004 National Household Survey on Drug Use and Health:
  - 31.8 million Americans had used a pain reliever non-medically at least once in their lifetimes
  - 7% increase from 2002
- 2002 DAWN data (ED visits):
  - 119,185 for narcotic analgesics (73% increase from 1999)

Drug Addiction is a Major Public Health Issue

- 2003 Treatment Episode Data Set:
  - Non-heroin opioids were primary drug of abuse for 9171 patients (534% increase from 1999)

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

What Makes Good Public Policy for Pain Management?

Reconciling the Numbers: The Principle of Balance

L I F E
PROJECT
Living Initiatives For End-Of-Life Care

- Public policy makers need to be mindful of the Principle of Balance:
  - Opioid analgesics need to be available for those with pain who need them
  - Opioid analgesics need to be unavailable for those with substance abuse problems who want to abuse or divert them

Criteria for Evaluating State Pain Policies

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

- Formulated by Dave Joranson and staff of Pain and Policy Studies Group, University of Wisconsin
- Surveys all state pain statutes, regulations, and guidelines
- 8 “positive” criteria, 9 “negative” criteria

Criteria for Evaluating State Pain Policies: Positive Criteria

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

- Controlled substances recognized as necessary for public health
- Pain management recognized as part of general medical practice
- Medical use of opioids recognized as legitimate professional practice
- Pain management is encouraged

Criteria for Evaluating State Pain Policies: Positive Criteria

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

- Practitioners' concerns about regulatory scrutiny are addressed
- Prescription amount alone insufficient to determine legitimacy of prescribing
- Dependence, tolerance ≠ addiction
- Other provisions that may enhance pain management

Criteria for Evaluating State Pain Policies: Negative Criteria

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

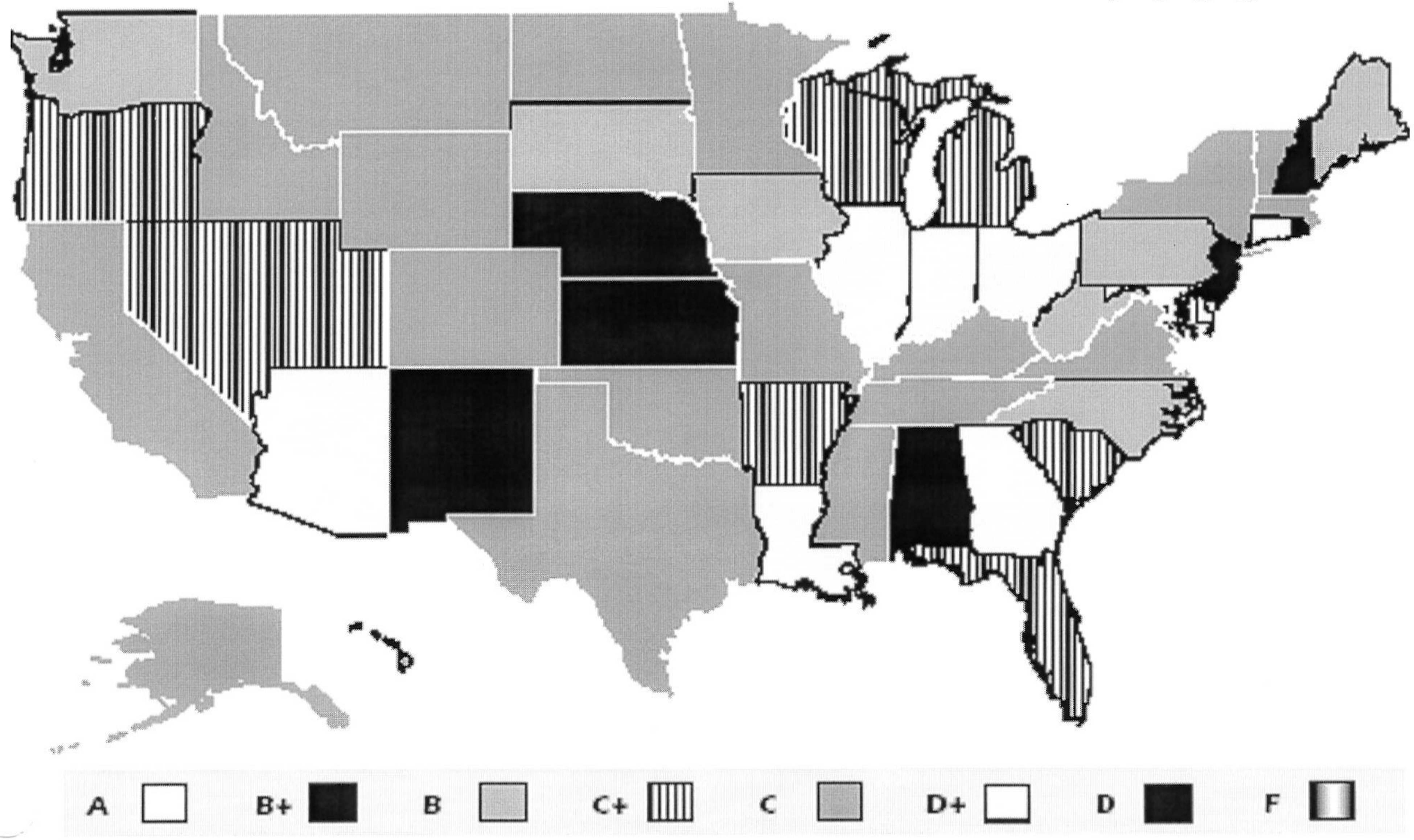
- Opioids are implied to be last resort
- Medical use of opioids implied to be outside legitimate practice
- Belief that opioids hasten death is perpetuated
- Dependence, tolerance = addiction
- Medical decisions are restricted

Criteria for Evaluating State Pain Policies: Negative Criteria

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

- Length of prescription validity unduly restricted
- Practitioners subject to other prescription requirements
- Other provisions that may impede pain management
- Provisions that are ambiguous

State Pain Policy "Grades"



2-14

"Positive" Kansas Policies

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

- Kansas pain policies meet all of the positive criteria except the first
- All of the remaining criteria are met only in pain management guidelines from our licensing boards
- Adding additional statements elsewhere in our policies could be beneficial

“Negative” Kansas Policies

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

- Prevention of Assisted Suicide Act: Perpetuates the belief that opioids hasten death (Principle of Double Effect)
- Principle of Double Effect is increasingly falling into disfavor--it has not been demonstrated to help with a significant problem in practice

Statutes Prohibiting Assisted Suicide

LIFE PROJECT
Living Initiatives For End-Of-Life Care

- Kansas passed anti-assisted suicide legislation in 1992 and 1997
- 1992 legislation made it a criminal offense to assist in a suicide
- 1997 legislation made it a civil offense, and provided for possibility of injunctive relief
- Contain "Principle of Double Effect" language

2-17

Principle of Double Effect

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

- Origins in Catholic moral theology (Thomas Aquinas)
- An act is morally permissible if:
  - The act itself is morally good or at least indifferent
  - Only the good effect is intended
  - The good effect is not achieved by way of the bad effect
  - The good result is proportionate to the bad result

Principle of Double Effect

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

- In most discussions of assisted suicide, this is invoked to alleviate provider fears
- Attempts to manage pain generally meet these requirements
- But, does this really provide any safe haven? How often does the "bad effect" occur in pain management?

Respiratory Depression and Opioids

- The fear underlying the development of the PDE is that giving opioids will depress respiration and kill the patient
- In opioid-naïve patients, this may not be an unreasonable fear
- In opioid-tolerant patients, respiratory depression can be incredibly difficult to produce via use of opioids

“Negative” Kansas Policies

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

- Medical Practice Act
  - “Unprofessional conduct” is grounds for sanction from the State Board of Healing Arts
  - One criterion for unprofessional conduct is “Prescribing, dispensing, administering, distributing a prescription drug or substance, including a controlled substance, *in an excessive, improper or inappropriate manner or quantity* or not in the course of the licensee’s professional practice

“Negative” Kansas Policies

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

- Medical Practice Act
  - This is an ambiguous provision within this act
  - It is not clear how “excessive”…quantity” is to be defined
  - Implication is that this can be determined by counting pills prescribed
  - But many patients with legitimate pain management concerns need large numbers of pills

Means of Improving Pain Management

- Development of practice guidelines
- Monitoring and continuous quality improvement
- Education of providers and patients
- Changes to policies and standards

Improving Pain Management Education

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

- We are making progress in basic medical/nursing school curricula
  - Highly dependent on having professors with an interest and enough influence to get this into the curriculum
  - Progress is slow, and amount of content is minimal, compared to prevalence of pain
- Need to continue working with faculty/administrators to improve content

Improving Pain Management Education

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

- Continuing Education is very important
  - Plenty of resources are available
  - Motivation is somewhat low because many healthcare providers think they are doing a good job
  - Some states have mandated continuing education in pain management/palliative care through legislation

Improving Pain Management Education

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

- We do not favor mandating continuing education
- The impact of this approach has not yet been fully evaluated
- Sets a precedent that may be undesirable
- May be able to use “half-steps”, such as specifically asking renewing practitioners to indicate hours of content in topic area

Changing Policies

LIFE PROJECT
Living Initiatives For End-Of-Life Care

- Address language related to Principle of Double Effect wherever it is found
  - Not necessary for enforcement of statute; its elimination would not change the standard by which practitioners would be judged
  - Does not materially help practitioners
  - Reinforces notion that opioids kill people—could have a chilling effect

2-22

Changing Policies

LIFE PROJECT
Living Initiatives For End-Of-Life Care

- Clean up language in Medical Practice Act, which says that “excessive” prescribing is grounds for disciplinary action
  - “Excessive” is very hard to define
  - Alternative is to refer to the standards set forth in the Controlled Substances Act

2-28

Changing Policies

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

- Open a dialogue with County and District Attorneys Association regarding process to be undertaken when deciding on charges against a practitioner
  - Would reassure practitioners that they will be judged by someone who has sufficient knowledge and experience
  - Would help prosecutors by establishing a standard process

Medicare/Medicaid Drug Coverage

LIFE PROJECT
Living Initiatives For End-Of-Life Care

- Restrictions on pain management drugs provided by Medicare and Medicaid could produce adverse outcomes for patients and the state
- Restricted access could impair pain management and result in greater costs from other parts of the programs
- Access to pain medications needs to be as complete and unrestricted as possible

2-30

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

"No patient should ever wish for death due to a physician's reluctance to use adequate amounts of effective opioids."

Jerome H. Jaffe, MD

Attachment 3
HHS 1-17-06

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

Critical Issues in End of Life
Advance Care Planning
Artificial Nutrition and Hydration

Testimony - January 17, 2006

John G. Carney, Vice President, Aging and End of Life
Center for Practical Bioethics

What makes good EOL policy?

- Good public policy follows common sense and what Americans/Kansans value
    - Family decision making
    - Physician Involvement
    - Good Pain Control and Symptom Management
    - Autonomy and Independence (Honoring Wishes)
    - Informed Consent
- Sound Policy guides good legislation

LIFE PROJECT
Living Initiatives For End-Of-Life Care

Policy and Practice
Values and Assumptions

- Professional Codes of conduct for practitioners exist to protect patients.
- Patients make their own health care decisions when able.
- End of life decisions are private matters between family members and their providers
- State statues shield healthcare from civil and criminal prosecution when acting in accordance with patients wishes

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

Policy and Practice
Values and Assumptions

3-4

- Persons unable to speak deserve an advocate to protect their interests A state's interest becomes active only upon an appointment of a guardian.
- Administration of artificial nutrition and hydration (ANH) is defined as treatment based in science; considered a medical intervention
- Guardianships appointment is a course of last resort.

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

What is the current status of advance healthcare directives in Kansas?

- Living Will Statute (KSA 65-28, 101)
- Power of Attorney Statute (KSA 58.625-632)
- Pre-Hospital DNR Statute (KSA 65.4941)
- Guardianship provision on withholding and withdrawal of hydration/nutrition (KSA 59-3075 (e)(7)(C)) – HB2307 (KS Judicial Council)

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

Kansas Advance Directives

- **Living Will Strengths**
  - Serves as a records of patient's wishes
  - Guides family and practitioners when patients cannot speak or loses capacity to judge
- **Living Will Weaknesses**
  - As a rule we don't do them/can't find them
  - Effective only upon incapacity
  - Not viewed by patient/family as process (changing over time)
  - Static - Cannot anticipate complex circumstances
  - Often onerous process defined by statute
  - Formats and legal language vary state by state

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

Kansas Advance Directives

- **Durable Power of Attorney for Health Care**

  a legal document used to appoint a particular person to make medical decisions for someone who is incapacitated. Appointee may be called a "surrogate," "health care proxy," "attorney-in-fact," or "healthcare agent."

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

Kansas Advance Directives

- **Durable Power of Attorney Strengths**
  - Clear authority for proxy to make all decisions even unanticipated
  - Powers can be restricted
  - Provides alternative to static document
  - Guide for proxy can be included in appointment

Kansas Advance Directives

- **Durable Power of Attorney Weaknesses**
  - Appointment often incidental with little guidance
  - Often ineffective in emergency situations
  - Practitioners often follow routine protocol without consulting proxy
  - Effective only upon incapacity

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

Kansas Advance Directives

- **"Do-Not-Resuscitate" Order:** instructions prepared by a physician directing health care providers to refrain from cardiopulmonary resuscitation (CPR) if patient has no breathing or heart beat.

Kansas Advance Directives

- **"Do-Not-Resuscitate" Strengths**
  - Specific Clearly written order by licensed provider limiting invasive attempts anticipated to be ineffective or contrary to patient wishes
  - Can avoid anguishing decisions to withdraw treatments later

Kansas Advance Directives

- **“Do-Not-Resuscitate” Weaknesses**
  - Difficult to honor in emergency situations
  - Limited in scope to specific heart/lung failure
  - Often misunderstood as blanket health care directive to limit treatments other than CPR.
  - Often does not transfer well between settings

Addressing the weaknesses
Retaining the strengths

- Recognize changes in aging and treatment
- Look to other states for models that work

3-14

Developing Issues at the End of Life

- Impact of Chronic Illness
  - Unknown disease trajectories and the impact of co-morbidities
  - In 2004 became leading cause of death in US
- Advancing age and increasing dementia impacts decision making capacity and shared decisions
  - DPOAHCs invoked before incapacity
  - 2004 Vermont Statute
- Diagnoses of minimally conscious states are unclear – terminal v. dependent on ANH

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

Recurring Issues at the End of Life

- Autonomy, Decisional Capacity, Informed Consent
  - Situational and Episodic Incapacity
  - Surrogacy and Shared Decision making
  - Changing health status
- Life Prolonging Treatment
  - Questions of Hydration and Nutrition
  - Treatment and Resuscitation Attempts
  - Disorders of Consciousness

Distinctions in Decision Making

- Determining Informed Consent
- Surrogate Obligation to perform substituted judgment
- Principle of "*best interest*" when substituted judgment cannot be determined
- Burden of proof – clear and convincing evidence in honoring wishes

Status of guardians in end of life decision making for wards

- Comprehensive overhaul of the statute in 2002
    - Limits and Exceptions clearly spelled out
    - Many states' silent on this issue

3-18

Protecting the interests of disabled who cannot speak for themselves

- One or all?
    - Personal/Family Decision
    - Medical Decision
    - Civil Rights Issue

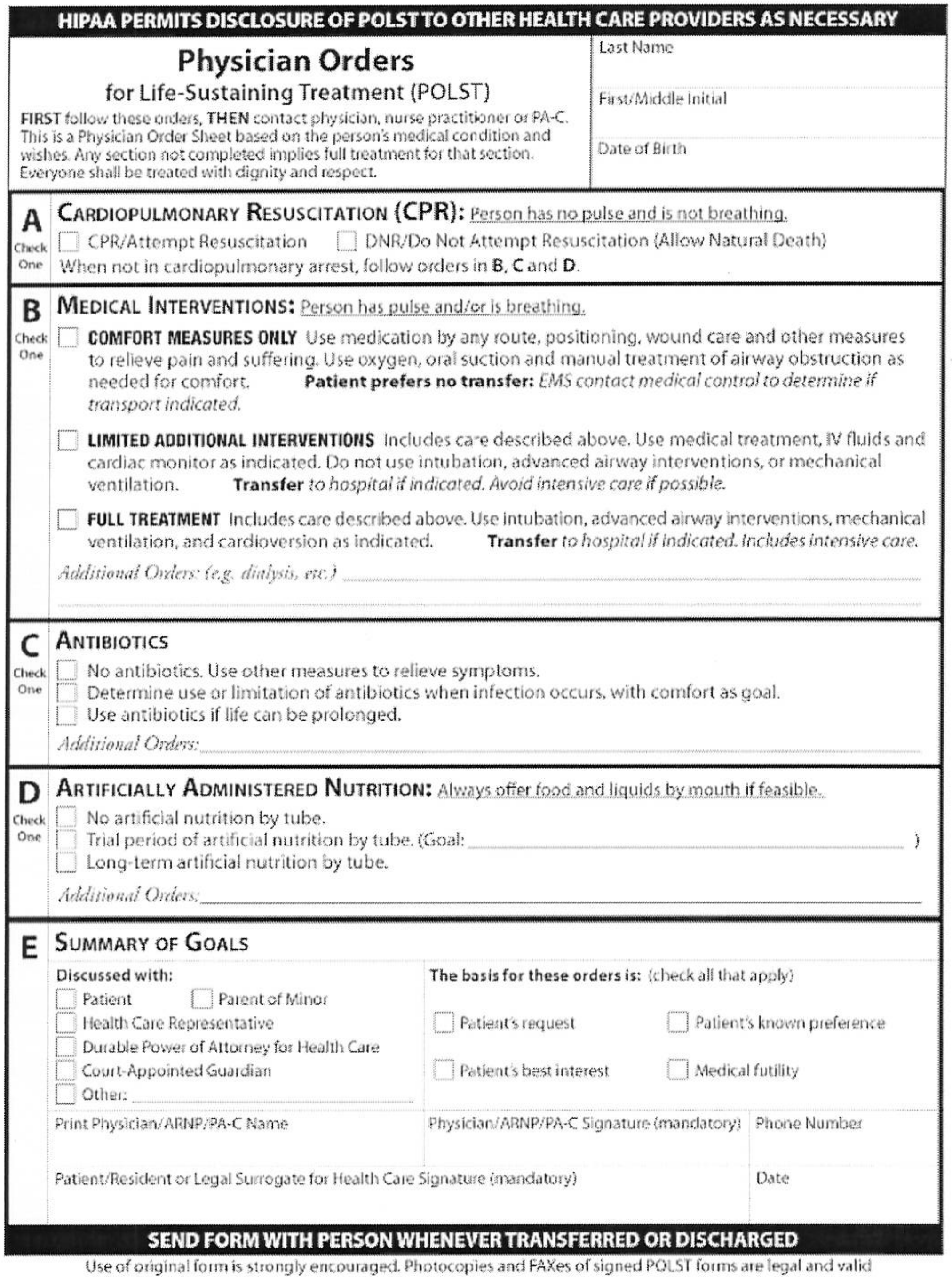
L I F E
PROJECT
Living Initiatives For End-Of-Life Care

Trends and Issues

- Alternatives/Advances in Advance Directives
    - Effective prior to complete incapacity
    - Digital Repositories (NC/VT Statutes)
    - Incorporate health care directive into DPOA
- Alternatives to Appointing Proxies
    - Combining statutes into one
- Alternatives to DNRs
    - POLST Forms
- Alternatives to Guardianships
    - Health care consent statutes

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

3-20



HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Physician Orders
for Life-Sustaining Treatment (POLST)

FIRST follow these orders, **THEN** contact physician, nurse practitioner or PA-C. This is a Physician Order Sheet based on the person's medical condition and wishes. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.

Last Name

First/Middle Initial

Date of Birth

A Check One

CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing.

☐ CPR/Attempt Resuscitation ☐ DNR/Do Not Attempt Resuscitation (Allow Natural Death)

When not in cardiopulmonary arrest, follow orders in **B**, **C** and **D**.

B Check One

MEDICAL INTERVENTIONS: Person has pulse and/or is breathing.

☐ **COMFORT MEASURES ONLY** Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, oral suction and manual treatment of airway obstruction as needed for comfort. **Patient prefers no transfer:** *EMS contact medical control to determine if transport indicated.*

☐ **LIMITED ADDITIONAL INTERVENTIONS** Includes care described above. Use medical treatment, IV fluids and cardiac monitor as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. **Transfer** *to hospital if indicated. Avoid intensive care if possible.*

☐ **FULL TREATMENT** Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. **Transfer** *to hospital if indicated. Includes intensive care.*

Additional Orders: (e.g. dialysis, etc.) ______

C Check One

ANTIBIOTICS

☐ No antibiotics. Use other measures to relieve symptoms.
☐ Determine use or limitation of antibiotics when infection occurs, with comfort as goal.
☐ Use antibiotics if life can be prolonged.

Additional Orders: ______

D Check One

ARTIFICIALLY ADMINISTERED NUTRITION: Always offer food and liquids by mouth if feasible.

☐ No artificial nutrition by tube.
☐ Trial period of artificial nutrition by tube. (Goal: ______)
☐ Long-term artificial nutrition by tube.

Additional Orders: ______

E

SUMMARY OF GOALS

Discussed with:
☐ Patient ☐ Parent of Minor
☐ Health Care Representative
☐ Durable Power of Attorney for Health Care
☐ Court-Appointed Guardian
☐ Other: ______

The basis for these orders is: (check all that apply)
☐ Patient's request ☐ Patient's known preference
☐ Patient's best interest ☐ Medical futility

Print Physician/ARNP/PA-C Name	Physician/ARNP/PA-C Signature (mandatory)	Phone Number
Patient/Resident or Legal Surrogate for Health Care Signature (mandatory)		Date

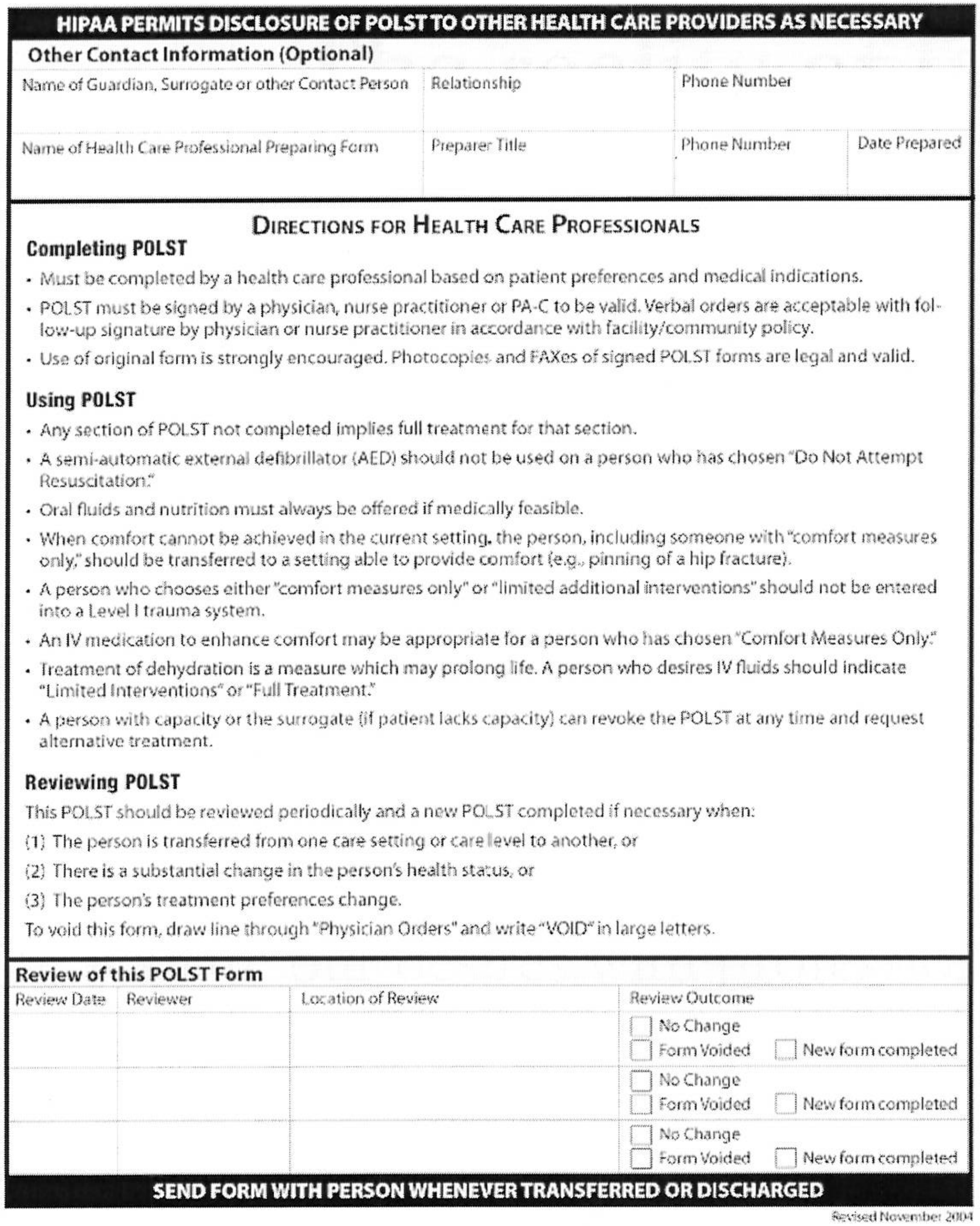
SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

Use of original form is strongly encouraged. Photocopies and FAXes of signed POLST forms are legal and valid

POLST
Side 1

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

3-24



HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Other Contact Information (Optional)

Name of Guardian, Surrogate or other Contact Person	Relationship	Phone Number	
Name of Health Care Professional Preparing Form	Preparer Title	Phone Number	Date Prepared

DIRECTIONS FOR HEALTH CARE PROFESSIONALS

Completing POLST

- Must be completed by a health care professional based on patient preferences and medical indications.
- POLST must be signed by a physician, nurse practitioner or PA-C to be valid. Verbal orders are acceptable with follow-up signature by physician or nurse practitioner in accordance with facility/community policy.
- Use of original form is strongly encouraged. Photocopies and FAXes of signed POLST forms are legal and valid.

Using POLST

- Any section of POLST not completed implies full treatment for that section.
- A semi-automatic external defibrillator (AED) should not be used on a person who has chosen "Do Not Attempt Resuscitation."
- Oral fluids and nutrition must always be offered if medically feasible.
- When comfort cannot be achieved in the current setting, the person, including someone with "comfort measures only," should be transferred to a setting able to provide comfort (e.g., pinning of a hip fracture).
- A person who chooses either "comfort measures only" or "limited additional interventions" should not be entered into a Level I trauma system.
- An IV medication to enhance comfort may be appropriate for a person who has chosen "Comfort Measures Only."
- Treatment of dehydration is a measure which may prolong life. A person who desires IV fluids should indicate "Limited Interventions" or "Full Treatment."
- A person with capacity or the surrogate (if patient lacks capacity) can revoke the POLST at any time and request alternative treatment.

Reviewing POLST

This POLST should be reviewed periodically and a new POLST completed if necessary when:

(1) The person is transferred from one care setting or care level to another, or

(2) There is a substantial change in the person's health status, or

(3) The person's treatment preferences change.

To void this form, draw line through "Physician Orders" and write "VOID" in large letters.

Review of this POLST Form

Review Date	Reviewer	Location of Review	Review Outcome
			☐ No Change ☐ Form Voided ☐ New form completed
			☐ No Change ☐ Form Voided ☐ New form completed
			☐ No Change ☐ Form Voided ☐ New form completed

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

Revised November 2004

POLST
side 2

LIFE
PROJECT
Living Initiatives For End-Of-Life Care

A Concluding thought…

I'm not afraid to die,
I just don't want to be there when
it happens.

Woody Allen

ISSUE NO. 4

A Design for Change

CRITICAL ISSUES IN CARE FOR CHRONICALLY AND TERMINALLY ILL KANSANS

— SECTION I —

L to R: Dr. Bob Twillman, University of Kansas Hospital, Meredith Mauck, Harry Hynes Memorial Hospice, Rep. Delia Garcia, Rep. Geraldine Flaharty and Rep. Nancy Kirk discuss end-of-life issues at the September 29, 2005, public policy forum held in Topeka.

Pain Management: Promising Practices and Frightening Fragmentation

The Problem

Pain is a major public health issue in our country and in our state.

- Chronic pain affects 35-50% of adult Americans (50-70 million people).[1]
- 80% of patients seek healthcare because of pain.[2]
- Over 30% of acute care patients report poor pain control.[3]
- 50% of dying patients report moderate to severe pain.[4]
- Unrelieved pain costs our economy over $100 billion each year.[5]
- 86% of dying cancer patients in Kansas experienced moderate to excruciating pain during the last months of life.[6]

> *"No patient should ever wish for death due to a physician's reluctance to use adequate amounts of effective opioids."*
>
> **—Jerome H. Jaffe, MD**

The Barriers and Concerns

There are few *actual* barriers to receiving good pain management in Kansas: No major provisions in any state statute, regulation or guideline significantly interfere with good pain management; disciplinary actions are relatively few; and interest is high for continuing education. There remain, however, numerous *perceived* barriers to treatment of pain in our state, from both the patient's and the healthcare provider's perspective, including:

- Healthcare professionals in our state often have not received focused training. They also lack knowledge needed

Helping all Kansans with advanced, chronic and terminal illnesses live with dignity, comfort and peace.

Project Office: 1901 University, Wichita, KS 67213-3325
Phone: (316) 263-6380 Fax: (316) 263-6542
Email: life@lifeproject.org Website: www.LIFEproject.org

LIFE PROJECT

Statewide Consumer Help Line: 1 (888) 202-LIFE (5433)
In Wichita: 219-3059 President & CEO: Donna Bales
Pain Management Hotline: (913) 588-3692

Attachment 4
HHS 1-17-06

to adequately manage their patients' pain. Many medical and nursing school curricula do not include adequate coverage of pain management.

- Many physicians fear the opinions of their peers, significantly impeding good pain management.

- Many physicians fear that the state licensing board or other regulatory or law enforcement agencies will investigate and sanction them.

- Patients fail to take medications as prescribed because of unwanted side effects, costs of medications or fear of addiction.

- Patients have difficulty finding physicians who will treat their pain adequately, especially in rural areas of the state.

- Patients have experienced problems with pharmacies filling prescriptions for pain medications.

- Patients have encountered obstacles with insurance companies and Medicaid paying for medications.

- Patients' expectations are low and they rarely serve as their own advocates.

- Physicians, patients and their families continue to harbor unrealistic fears of addiction and misconceptions about opioid analgesics and their physiologic effects.

- Costs of medications are a serious concern for many Kansans.

The Progress

Over the past five years Kansas has made great strides in implementation of adequate public policies regarding pain management and has been awarded high marks for our efforts by the Pain & Policy Studies Group at the University of Wisconsin.[8]

Clearing up the Misconceptions about Physical Dependence, Tolerance and Addiction:

Three distinct terms - physical dependence, tolerance and addiction - have been used interchangeably by the public, healthcare professionals, scientists and regulators for years. These misconceptions have also had the negative outcome of leaving patients with severe under-treated pain, because they (or their healthcare provider) fear that opioids will cause addiction.

Key Definitions: [7]

Physical Dependence: "A physiologic state of neuro-adaptation, which is characterized by the emergence of a withdrawal syndrome if drug use is stopped or decreased abruptly." Physical dependence is an expected result of opioid use, and physical dependence, by itself, does not equate with addiction.

Tolerance: "A physiologic state resulting from regular use of a drug in which an increased dosage is needed to produce the same effect, or a reduced effect is observed with a constant dose." Tolerance may or may not be evident during opioid treatment and does not equate with addiction.

Addiction: "A neurobehavioral syndrome, with genetic and environmental influences, that results in psychological dependence on the use of substances for their psychic effects characterized by compulsive use despite harm."

Kansas state licensing boards have been proactive in adopting policies and guidelines for the treatment of pain, including the *Joint Policy Statement of the Boards of Healing Arts, Nursing and Pharmacy on the Use of Controlled Substances for the Treatment of Pain.* This landmark state policy, the first of its kind in the nation to address all types of pain – chronic, acute and end of life – was adopted in 2002.[9] The policy reflects the depth of commitment and desire that Kansas licensing boards have to supporting, encouraging and expecting quality and excellence in the assessment and management of pain. The Kansas State Boards of Healing Arts and Nursing also adopted similar guidelines for their licensees. [10, 11]

> *"A person's report of pain is the optimal standard upon which all pain management interventions are based."*
>
> **—Joint Policy Statement**

The Recommendations

I. Improve Pain Management Education

Mandated pain management education may not be the solution, as the impact of this approach has not yet been fully evaluated. Initiating "half-steps," such as specifically asking renewing practitioners to indicate hours of content in the area of pain management, might be a more acceptable approach.

We are making progress in medical/nursing school curricula offerings, but we need to continue working with faculty and administrators to improve content.

II. Change and Revise Policies

Address policy language related to the Principle of Double Effect [11]*, wherever it is found.* This principle unintentionally reinforces the notion that opioids kill people. Its reference is not necessary for enforcement of state statutes, and its elimination would not change the standard by which practitioners are judged.

Clean up language in the Medical Practice Act, which says that "excessive" prescribing is grounds for disciplinary action. "Excessive" is very hard to define. An alternative is to refer to the standards set forth in the Controlled Substances Act.

Open a dialogue with the Kansas County and District Attorneys Association and continue a dialogue with the Kansas Attorney General regarding the process to be undertaken when deciding on charges against a practitioner. Establishing a standard process would give reassurance to practitioners that someone who has sufficient knowledge and experience will judge them.

Exercise great caution in considering adoption of prescription monitoring programs, whose intent is to prevent diversion and abuse. There are database programs now in place, in approximately half the states, that track either Schedule II medications only, or Schedule II, III and IV medications. These databases can be used to identify patients engaging in suspect behavior and prescribers whose practices are questionable.

Congress passed the National All Schedules Prescription Electronic Reporting Act of 2005 earlier this year, which provides grants to states to establish and maintain these programs.

Kansas should exercise great caution in considering the implementation of a prescription monitoring program. Outcomes are hard to track, and one intervention is not appropriate everywhere. One unintended consequence may be restricted access for pain patients due to a chilling effect. Much analysis remains to be done, and other critical issues to consider include:

–Who has access to data?

–How timely is access to data?

–Is the program administered by health authorities or law enforcement?

–What requirements must be met for law enforcement to access data?

–Is there an advisory group of practitioners to oversee the program and evaluate outcomes?

Assure that Medicare and Medicaid beneficiaries have access to pain medications. Access to pain medications, including opioid analgesics, needs to be as complete and unrestricted as possible for beneficiaries of these programs. Restrictions imposed on pain management drugs provided by Medicare and Medicaid could produce adverse outcomes for patients and the state. Further, restricted access could impair pain management and result in greater costs from other parts of these programs.

References:

[1] American Pain Foundation (2000). Facts about Pain. Found at http://www.painfoundation.org/page.asp?file=Library/FastFacts.htm

[2] Koch, H (1986). The management of chronic pain in office-based ambulatory care: National Ambulatory Care Survey. Advanced Data from Vital and Health Statistics, No. 123. National Center for Health Statistics, Department of Health and Human Services, Public Health Service Publication No. 86-1250. Hyattsville, MD: Public Health Service.

[3] McNeill, JA, Sherwood, GD, & Starck, PL (2004). The hidden error of mismanaged pain: A systems approach. Journal of Pain and Symptom Management, 28(1), 47-58.

[4] The SUPPORT Study (1995).

[5] National Institutes of Health (1998). New directions in pain research. Found at http://www.niams.nih.gov/rtac/funding/grants/pa/pa_98_102.pdf.

[6] Kansas Department of Health & Environment (2000). Behavioral Risk Factor Surveillance Survey (as reported by survivors of Kansans who died with cancer).

[7] All taken from Joint Policy Statement of the Boards of Healing Arts, Nursing and Pharmacy on the Use of Controlled Substances for the Treatment of Pain (2002). Found at www.ksbha.org/misc/jointpainmgmt.html.

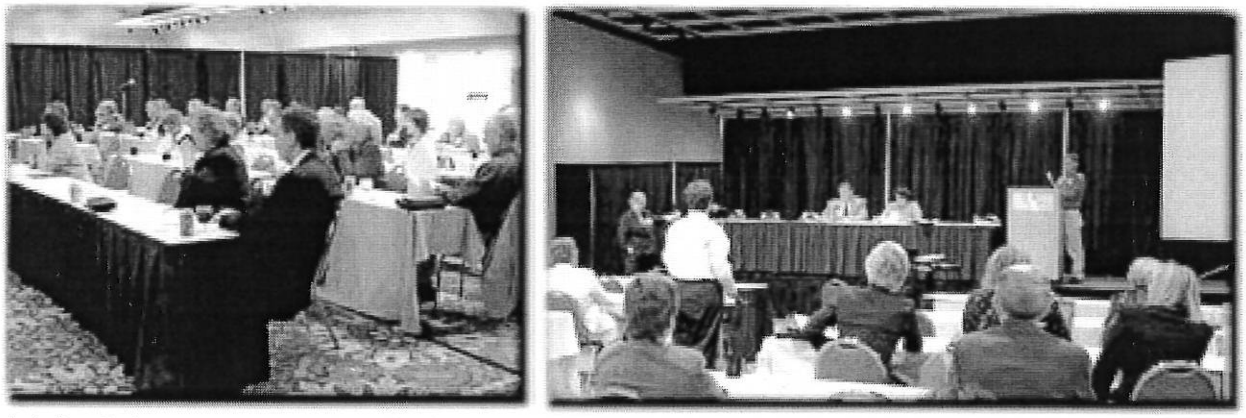
[8] Pain & Policy Studies Group, University of Wisconsin Comprehensive Cancer Center (2004). Achieving Balance in State Pain Policy: A Progress Report Card. Found at www.medsch.wisc.edu/painpolicy/2003_balance/prc2003.pdf.

[9] Joint Policy Statement.

[10] Kansas State Board of Nursing (2001). Guideline for Pain Management. Found at www.ksbn.org/legal/task_force_pain_guidelines.pdf.

[11] Kansas State Board of Healing Arts (1998). Guidelines for the Use of Controlled Substances for the Treatment of Pain. Found at www.ksbha.org/misc/painmgmt.htm.

[12] McIntyre, Alison, Doctrine of Double Effect. Stanford Encyclopedia of Philosophy (Summer 2005 Edition). Found at http://plato.stanford.edu/entries/double-effect/.



Left: *State leaders participate in a public policy forum sponsored by the Kansas LIFE Project on September 29 at the Capitol Plaza Hotel in Topeka to learn more about issues related to pain management, advance care planning and artificial nutrition and hydration.*
Right: *Kathy Greenlee, Kansas Long-Term Care Ombudsman, addresses the panel, consisting of (L to R) Donna Bales, President/CEO of the Kansas LIFE Project, Representatives Bob Bethel and Nancy Kirk, and John Carney, Vice President on Aging and End of Life at the Center for Practical Bioethics.*

Advance Care Planning: Processes and Documents

Advance care planning generally deals with three types of end-of-life decision-making processes and documents. Kansas has statutes governing all three types of decision-making.

The first type, known commonly as the ***living will***, describes what type of care an individual seeks or expects at the end of life. Usually in writing, the living will takes effect when two physicians agree that the person is terminally ill.

The second document, the ***durable power of attorney for health care***, names a surrogate or agent to make healthcare decisions for an individual when, and only when, the individual is unable to do so.

The third advance care planning tool, or advance directive, is a ***Do Not Resuscitate order*** (DNR). This document is signed by a patient's physician and directs the type of emergency care that an individual receives at the end of life. This order may be issued either in medical settings or outside of them.

Advance care planning documents serve a number of noble and necessary purposes.[1] They:

- Seek to preserve self-determination.
- Express and give effect to end-of-life preferences.
- Offer protection from maltreatment.
- Relieve anxiety and facilitate patient choice.
- Help loved ones when they must make treatment decisions.
- Protect financial resources.
- Decrease the risk of litigation.
- Can foster necessary communication.

Since the introduction and legal sanction of advance care planning documents in the US more than 30 years ago, evidence for their merits has grown steadily.

Although only limited studies exist, data support the contention that those with advance directives, when professional caregivers know and honor them, can lead to fewer deaths in the hospital, fewer intensive care days, fewer end-of-life resources expended, and increased family satisfaction.[2,3]

Unfortunately, despite more than three decades of work, most Americans do not utilize these protections.

The Problem

• Of the 2.5 million people who die each year in the US, only about one-half million actually have written advance directives. Without the important conversations and/or document, family and professional caregivers are left in uncertain territory when attempting to honor a patient's dying wishes.[4] In Kansas, it is estimated that fewer than 1/3 of all Kansans have advance directives.

• Eighty percent of those who die in hospitals are without the capacity to make decisions and many of these are on life-support.[5]

• A growing number of frail elderly do not have capacity to make decisions at the end of life. The US is an aging society and growing older. Dementia affects half of persons over the age of 85. Proportionately, that population is the fastest growing segment in society.[6]

• How we die is changing. Rather than dying from fatal episodes of acute illness and traumatic attacks, more people live for extended periods of slowly declining health. In 2004, for the first time,

Advance Directives Weaknesses:

Living Will Weaknesses

- As a rule, people don't do them or can't find them when they are needed.
- Too often, living wills are viewed by the patient/family as static and not as a process changing over time.
- The document cannot anticipate complex circumstances and is often too vague to be meaningful.
- The living will is often a complicated process defined by statute.
- Formats and legal language vary state by state.
- Many people confuse the living will with a durable power of attorney for health care decisions.
- The living will is only activated upon a terminal diagnosis.

Durable Power of Attorney for Health Care Weaknesses

- The agent is named but not often given adequate guidance regarding the person's wishes and choices for care.
- They are often ineffective in emergency situations.
- Practitioners often follow routine protocol without consulting the agent.
- The durable power is effective only upon incapacity of the patient, rather than in diminishing states (most common for those affected by dementia).

"Do-Not-Resuscitate" Weaknesses

- A DNR is difficult to honor in emergency situations, especially pre-hospital or out of hospital.
- DNRs are often misunderstood as a blanket healthcare directive to limit treatments other than cardio-pulmonary resuscitation (CPR).
- DNRs are limited in scope to specific heart/lung failure, rather than other conditions.
- A DNR may or may not be understood or agreed to by the agent or proxy decision-maker named in a durable power of attorney for health care (DPOAHC).
- DNRs often do not transfer well between settings.

chronic illness became the leading cause of death in the US.[7] This living at the end of life with chronic illnesses will continue long into the future. Most of us will die of complications from chronic illnesses, often with slow and uncertain disease paths affected by dementia while being caregiver dependent.

The Barriers and Concerns

Since the tragic case of Terri Schiavo captured media attention and America's legal and political spotlight, significant focus nationwide has been given to legislative proposals to address/prevent similar situations. Unfortunately, the complex ethical issues of self-determination, surrogate decision-making and judging between terminal vs. disabled states, when reduced to sound bites, remain divisive. Well-intentioned legislative solutions need to be carefully crafted to find common ground.

In addition, public policymakers and healthcare ethicists have studied the reluctance of Americans to implement advance directives and, in recent months, identified a number of barriers as to why more Americans don't complete advance directives.

Those issues include:

- Documents cannot anticipate unknown future clinical situations or medical conditions, nor clarify unclear preferences.

- Treatment preferences cannot be clearly conveyed in a brief, "check box style" format.

- Too often, individuals do not talk about their choices with healthcare providers and family members.

- The result of poor communication is that there is little effect on surrogate decision-making and little impact on care for incompetent patients. Surrogates then act in the "best interest" rather than in substitution of the patient.

- Side benefits are uncertain.

- Finally, death remains a taboo subject in most homes dominated by the western medical model. As one source put it, *"Americans are the only people on the planet who believe death is an optional event."*

The Progress

Fortunately, the reluctance of Americans to discuss advance care planning with their professional caregivers has received attention at the national level. Proposed legislation is currently under consideration by Congress allowing for Medicare payments to physicians for end-of-life consultations. While that legislation is uncertain, given the current fiscal environment, it nonetheless attempts to address the concern directly.

In addition, there has been a surge in the numbers of Americans reportedly completing advance directives as a direct result of the Terri Schiavo case. Some estimates say that as many as 25% of Americans may now have them in place (a 67% increase in less than a year).

Several national and state electronic repositories have recently been established. These repositories hold electronic versions of advance care documents for patients and agents. Current utilization, though limited, is growing. Web-based retrieval helps remote family members and professional caregivers when the information is not with the patient or a hard copy cannot be located.

Forms for naming an agent at the time of the document's execution, rather than waiting for complete patient incapacity, are becoming more commonplace as well. Specific statutory language however, may need to be revised.

The Recommendations

I. Reduce barriers to advance care planning document retrieval

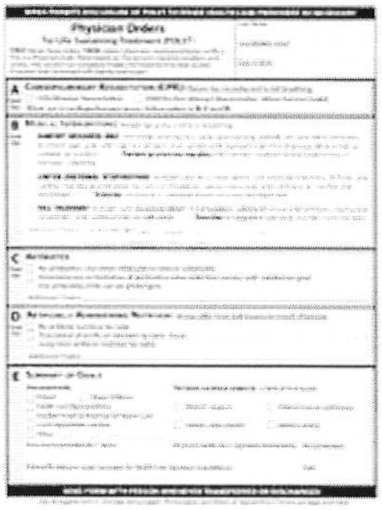
Explore state initiatives (e.g. Arizona, North Carolina, Vermont, West Virginia) regarding statewide efforts to encourage electronic storage and retrieval of advance care planning documents.

II. Change and Revise Policies

Allow for the appointment of durable powers of attorney prior to incapacity if a person so chooses. To protect the interests of all patients, surrogate decision-makers should, at a minimum, meet the requirements set by guardianship statute to involve the patient appropriately in all healthcare decisions related to their care and treatment.

Respect and honor the wishes of all persons. Kansans are encouraged to make their wishes clear via verbal and written directives and by naming a durable power of attorney for health care. Healthcare providers are encouraged to initiate these conversations with patients.

Ensure that all persons, including minors, have access to life-sustaining treatments inside and outside of medical settings based on their family and physician decisions.



Left: A sample Physician's Order for Life Sustaining Treatment form.
To review a sample POLST form, contact life@lifeproject.org.

Proactively address the growing variety of life-sustaining measures (beyond cardio-pulmonary resuscitation) to ensure that chronically ill and dying persons are afforded appropriate comfort measures and non-burdensome treatments. Explore and study the Physician Order for Life Sustaining Treatment (POLST) form or one of its iterations. These forms encourage important conversations between healthcare providers and patients and address the appropriateness of critical interventions for seriously ill patients. This may not require statutory change, as evidenced by the State of Oregon.

Protect disabled and cognitively impaired persons regarding their end-of-life wishes and work to assure that these wishes are appropriately expressed and honored.

Conduct a comprehensive review of all Kansas statutes regarding end-of-life care, including access to palliative care, advance directives, appointment of agents, in and outside of medical facility healthcare directives (and physician orders), organ donation, and disposition of the body to determine need for additions, updating or revisions.

References:

[1] The President's Council on Bioethics (2005). Taking Care: Ethical Caregiving in Our Aging Society. Found at www.bioethics.gov/reports/taking_care/index.html.

[2] Hickman, Susan E., et al., "Hope for the Future: Achieving the Original Intent of Advance Directives" (2005). Improving End of Life Care: Why Has It Been So Difficult? Hastings Center Report Special Report 35, no. 6: S26-S30.

[3] Molloy, D.W. et al., "Systematic Implementation of an Advance Directive Program in Nursing Homes: A Randomized Controlled Trial," Journal of the American Medical Association 283, no.11 (2000): 1437-44.

[4] The President's Council on Bioethics (2005).

[5] Center for Practical Bioethics, Kansas City, Missouri (2003). Caring Conversations. Found at www.practicalbioethics.org.

[6] Centers for Disease Control (2004). State of Aging and Health in America. Found at www.cdc.gov/aging/pdf/State_of_Aging_and_Health_in_America_2004.pdf.

[7] CDC (2004).

John Carney, Vice President on Aging and End of Life, the Center for Practical Bioethics, presents an overview of the issues to state leaders during the September 29 public policy forum.

Artificial Nutrition and Hydration: Choices and Obligations

With the advance of medical technology, the possibility of sustaining and maintaining human functions has clouded the definition of what it means to be alive. While the Constitutional right to refuse treatment may remain a "settled" matter, continuing to provide nutrition to someone in a permanently unconscious state whose wishes are indiscernible or unknown can deeply divide families, voters, courts and elected officials.

Central to the controversy surrounding Terri Schiavo's case were the differing interpretations of her preferences for treatment-being fed indefinitely via artificial nutrition and hydration. There were questions about her expressed wishes, because she did not have written advance directives. There were challenges made to the diagnosis of persistent vegetative state, argued by some to be a terminal condition, though not imminently life-threatening and resulting in endless legal motions and court proceedings. Disability rights groups also argued that Terri's "disability" demanded special protections in order to ensure that her life, however compromised, was not cut short.

> *"Continuing to provide nutrition to someone in a permanently unconscious state whose wishes are indiscernible or unknown can deeply divide families, voters, courts and elected officials."*

A number of public policy questions rise from the heart of these issues. Not only do we struggle with whom should make the decision, we also struggle with making the "right" decision, in ensuring the state's interest to protect those who cannot speak for themselves and in reconciling the deeply personal and emotional struggle resulting from withholding and withdrawing treatments.

The Problem

The difficulty in developing sound public policy related to the administration of artificial nutrition and hydration – especially for those under the protection of the state who cannot speak for themselves - is to balance the private interests of individuals with the public good. The weighing of the benefits and burdens of each must be considered on an ongoing basis. Rights of privacy and personal protection address not only self-determination, autonomy, pursuit of meaning and the definition of life itself, but encompass broader dimensions of society and culture (community standards). The problem of balance involves religious and spiritual values, existential and economic considerations and convictions about the role and obligation of government to intervene and provide support to those in need.

The issue is also one of medical vitalism, which refers to attempts to preserve the patient's life in and of itself without any significant hope for recovery.[1] Many faiths, including the conservative Catholic tradition, reject this position and, instead, argue for a "purpose in being" that goes beyond mere bodily function. Some disability groups argue that quality of life is relative in nature and that no one can judge for another about their quality of life.

Unfortunately, existing medical technology now possesses the capabilities of indefinitely maintaining life functions for those who have no medically based expectation of recovery. The problem, then, in this light is not so much about balancing the rights of privacy in administering or withholding treatment as it is about the definition of life itself and the obligations and limits of government to protect those interests, especially for those who cannot speak for themselves.

The Barriers and Concerns

For most Americans, healthcare is a private matter between doctor and patient and between patient and family. Across the political spectrum, government's insertion or "intrusion" in private matters is for the most part considered unwarranted. The exceptions deal primarily with protections for the vulnerable.

Generally, matters of life and death decision-making are left to healthcare professionals and the patients and families they serve. These decisions are governed and protected by professional licensure laws, scope of practice and certification standards and accreditation. Disagreements about end-of-life treatment directives get resolved at the bedside in most cases. It is in the cases where irresolvable disputes arise that the legal system gets involved. Every effort should be made to determine the patient's wishes, especially as the patient's capacity diminishes, burdens of treatment increase, and locations of care become less accute.

"Disagreements about end-of-life treatment directives get resolved at the bedside in most cases. It is in the cases where irresolvable disputes arise that the legal system gets involved."

In addition, unforeseen and unanticipated developments in technology and medical interventions require the need for a trusted surrogate to be named and to be familiar with the wishes of the patient when he/she can no longer speak.

Post-Schiavo attention by medical practitioners to artificial nutrition and hydration (ANH) underscores that a decision to administer ANH involves "substantial risks and burdens" to the patient and in nearly every case is not judged an emergency.[2] Weighty consideration about the treatment goals should accompany any recommendation or request.

The Progress

In 2002, Kansas legislators approved a completely revised Kansas Guardianship statute. While most guardians are family members already, provisions in the new law require guardians to get to know their wards similarly to the ways that family members know one another. This statute also requires guardians, to the best of their ability, to make end-of-life decisions for their wards that reflect the wishes of the ward (substituted judgment). When that cannot be achieved, the guardian is required to make decisions in the ward's "best interest," in consultation with medical professionals. Revisers of the statute took into consideration that end-of-life decisions were, first and foremost, personal and family decisions and then medical decisions. Obligations of guardians and professional caregivers were assumed to protect the interests of the ward.

In the summer and fall of 2005, a committee of the Kansas Judicial Council studied the statutory language governing the authority and responsibility of guardians in making decisions about administering artificial nutrition and hydration for wards of the court. The group's recommendations will be forwarded to the legislature when it returns in 2006.

Statutory language for the provision of ANH for persons who do not have an advanced directive in place at the time of incapacity has been proposed by some states.

The Recommendations

I. Support the Kansas Judicial Council recommendation on clarifying language regarding the obligations of guardians on the administration of artificial nutrition and hydration (ANH) for wards of the court.

II. Provide opportunity and hearing for parties interested in developing statutory language in the provision of ANH for all Kansans without a durable power of attorney for health care (DPOAHC) or advance directive should their health condition warrant.

III. Conduct a comprehensive review of all Kansas statutes regarding end-of-life care to determine need for additions, updating and/or revisions. This review should include a review of access to palliative care, advance directives, appointment of agents, in and outside of medical facility healthcare directives and physician orders, organ donation and disposition of the body.

References

[1] Nairn, TA., Health Progress, 1997 Nov-Dec; 78(6):36-9,42, *Reclaiming our moral tradition. Catholic teaching calls us to accept the limits of medical technology,* Catholic Theological Union, *Chicago, IL.*

[2] Casaratt, David, MD, MA, December 15, 2005, University of Pennsylvania Health Systems, Philadelphia, PA, http://www.uphs.upenn.edu/news/

The LIFE Project would like to acknowledge Bob Twillman, Co-Chair of the LIFE Project Pain Management Task Group and Pain Management Program Director at the University of Kansas Medical Center, and John Carney, Chair of the LIFE Project Public Policy Task Group and Vice President on Aging and End of Life at the Center for Practical Bioethics, for their expert contributions to this publication.

Published January 2006

4-11

Funding for this project is provided in part by a grant from the American Alliance of Cancer Pain Initiatives (AACPI), University of Wisconsin-School of Medicine, Madison, WI

Other Acknowledgements:

The LIFE Project gratefully acknowledges additional funding and support from United Methodist Health Ministry Fund, K.T. Wiedemann Foundation, Harry Hynes Memorial Hospice, Foundation for Hospice Care, Kansas Department on Aging, PhRMA, Kansas City Cancer Center, Northwest Kansas AHEC, Lighthouse Hospice, Kansas Association of Family and Community Education and Midland Hospice.

All contributions to the LIFE Project Foundation, a 501 (c) 3 organization, are tax deductible. We invite you to become a "Friend for LIFE" by sending tax deductible contributions to: LIFE Project, 1901 University Ave., Wichita, KS 67213.

LIFE Project Partners:

Governmental Agencies:

Kansas Association of Area Agencies on Aging
Kansas Board of Emergency Services
Kansas Department of Health & Environment
Kansas Department of Social & Rehabilitation Services
* **Kansas Department on Aging**
* **Kansas Foundation for Medical Care, Inc.**
Kansas Insurance Department
Kansas Office of the Attorney General
Kansas Office of the Governor
Kansas Office of the Long-Term Care Ombudsman
Kansas State Board of Healing Arts
Kansas State Board of Nursing
Kansas State Board of Pharmacy
Kansas State Library

Academic Institutions:

Emporia State University
Johnson County Community College
Kansas State University, Extension – Research Services
Landon Center on Aging at University of Kansas
University of Kansas School of Medicine
University of Kansas School of Nursing
Wichita State University

Consumer Advocacy:

AARP Kansas
Disability Rights Center of Kansas
Kansas Advocates for Better Care

Other Partners:

* **American Alliance of Cancer Pain Initiatives**
American Cancer Society - Heartland Division
The Center for Practical Bioethics
* **The Foundation for Hospice Care, Inc.**
* **K.T. Wiedemann Foundation**
Kansas Health Ethics
Kansas Health Institute
Kansas Humanities Council
Kansas League of Women Voters
* **Northwest Kansas Area Health Education Center**
* **PhRMA**
* **United Methodist Health Ministry Fund**

Media Organizations:

Kansas Association of Broadcasters
Kansas Press Association
Kansas Public Radio
Kansas Public Television - KPTS
Kansas Senior Press Services

Medical Providers:

* **Faith Home Health Hospice**
* **Harry Hynes Memorial Hospice**
* **Hospice Services, Inc.**
* **Kansas City Cancer Center**
* **Lighthouse Hospice**
Midland Hospice
Shawnee Mission Medical Center
* **South Wind Hospice**
University of Kansas Medical Center
Via Christi Regional Medical Center
Wesley Medical Center

Professional Associations:

* **Kansas Association for Family & Community Education**
Kansas Association of Homes & Services for the Aging
Kansas Association of Osteopathic Medicine
Kansas Chapter, National Association of Social Workers
Kansas Funeral Directors & Embalmers Association
Kansas Health Care Association, Inc.
Kansas Home Care Association
* **Kansas Hospice and Palliative Care Organization**
Kansas Hospital Association
Kansas Medical Society
Kansas Organization of Nurse Leaders
* **Kansas Pain Initiative**
Kansas Pharmacists Association
Kansas State Nurses Association

Caring Communities:

Clay Center, Dickinson County, Dodge City, Emporia, Garden City, Great Bend, Greenwood County, Hays, Hutchinson, * **Jackson County**, Jefferson County, Junction City, Kansas City, Lawrence, Liberal, Manhattan, Morris County, Nemaha County, Northeast Kansas, Newton, Norton, Osborne County, Phillipsburg, Pittsburg, Pratt, Rush County, Salina, Shawnee Mission, Topeka, Wamego/Pottawatomie County, Washington County, Wichita

* **Denotes FRIENDS FOR LIFE Contributing Partners --who have made direct financial contributions during 2005**

Living Initiatives For End-of-Life Care

Helping Kansans with advanced chronic and terminal illnesses live with dignity, comfort and peace.

LIFE
PROJECT

The LIFE Project addresses public policy, professional education, and public engagement. Visit our website at www.lifeproject.org or call us at (888) 202-LIFE (5433) or, in Wichita, at (316) 219-3059.