

A Design for Change

ISSUE NO. 3

END OF LIFE CARE ISSUES IN KANSAS



LIFE Matters:

Achieving Excellence in Care for Kansans with Advanced Chronic and Terminal Illnesses

Since 1998, the Kansas LIFE Project has been working to help Kansans and families with advanced chronic and terminal illnesses to live with dignity, comfort and peace. More than 100 LIFE Project Partners work together to implement initiatives that address public policy, professional expertise and public engagement that support and advance excellence in care.

Kansas Town Hall Meetings Summer 2004

During the summer of 2004, the Kansas LIFE Project and LIFE's *Caring Communities*, grassroots action groups, convened a series of town hall meetings in numerous locations all across Kansas. More than 300 Kansans participated in these

"Thinking about, planning for and talking about your wishes for care at the end of life will not shorten your life by one day."

—Kansas Town Hall Participant

meetings and included citizens from rural and urban communities, healthcare professionals, African Americans, Native Americans, Hispanics, other minority groups, young and old and healthy and ill.

Goals of the Town Hall Meetings

The goals of the meetings were to:

- 1) listen to and learn from Kansans about hopes, expectations, fears and concerns about living well with chronic and/or terminal illnesses;
- 2) promote resources and information that empower Kansans to serve as good advocates for themselves and those they care for and about; and,
- 3) take what we hear and learn to inform and drive LIFE's future plans for action.

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



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



What We Heard

What we heard through these meetings teaches us that Kansans, like citizens across the country, continue to face the challenges that come with living well when seriously ill. As Kansans shared with us in these meetings, key themes were clearly present. This report will share those key themes, reflect on the context and environment within which the LIFE Project continues its work and offers guidance to the LIFE Project Partners and LIFE Project Task Groups as we plan for continuing efforts to help Kansans living with advanced chronic and terminal illnesses to live with dignity, comfort and peace.

Kansans give us clear and consistent messages about their hopes and fears when living with serious illness. We hope to live without pain and be kept comfortable, to stay at home with family and friends, to have our wishes honored, to be treated with respect, to maintain some sense of control over our own care, to understand what is happening, to have others with us and to not spend too much money. Our fears are a near-mirror image of these hopes. We fear that our wishes will not be honored, that we will live with untreated and undertreated pain, that we will not be treated with respect, that we will be moved to an environment other than one

“I have talked with my family and my physician. All of them assure me that my wishes will be followed. This is really important to me and it means a lot that everyone agrees.”
—Kansas Town Hall Participant

we freely choose, that we will be alone and that we will spend too much money.

As studies and data continue to emerge across the country, the hopes and experiences of Kansans are much like those of others. Our hopes *and* fears grow from our experiences with those we know and love and our wishes and concerns about our own care. Kansans lack complete confidence that the kind of care they hope to receive as they near the end of life will match the kind of care they do actually receive. Studies show that these fears are grounded in reality.

In spite of Americans’ wishes, too many still die in institutions, with inadequate pain management. Our wishes are too seldom known and honored and family members, too often, do not receive the support and information they feel they need. We also know that progress is being made because of the work of the LIFE Project Partners.

Now, the challenge to the LIFE Project Partners, Task Groups and *Caring Communities* is to take the messages that Kansans have given us and plan actions that help us to continue our collaborative efforts to most efficiently address Kansans’ hopes, fears and concerns.

The voices of our citizens offer direction and fuel our passion as we continue this work to aggressively pursue the realization of Kansans’ hopes and the easing of Kansans’ fears.

LIFE Project Town Hall Meetings—Summer 2004



Kansans Speak Out

As Kansans live with advanced chronic and terminal illnesses, we hope to:

- Live without pain and be kept comfortable
- Stay at home with family and friends
- Have our wishes honored
- Be treated with respect
- Maintain some sense of control over our own care
- Understand what is happening
- Have others with us
- Not spend too much money

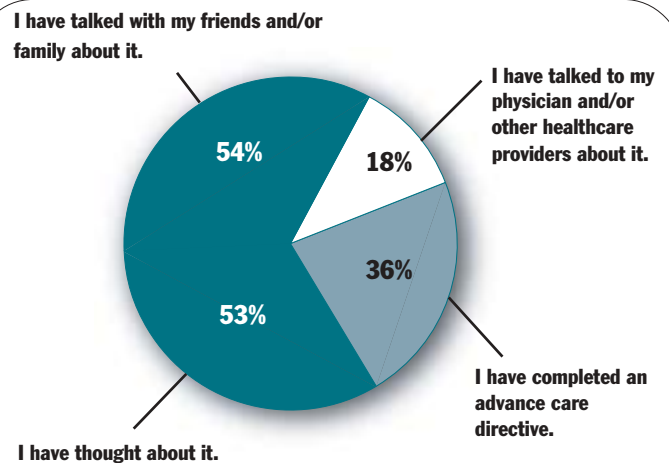
As Kansans live with advanced chronic and terminal illnesses, we fear:

- That our wishes will not be honored
- Having pain that is not well-treated
- Not being treated with respect
- Being moved to an environment not of our choosing
- Being alone
- Spending too much money

Other common themes:

- A majority of Kansans lack complete confidence that our wishes and hopes will be fully realized.
- When we are in an institution, those who have an advocate, visitors and a family receive the best care.
- We want to be told the truth about our medical conditions in ways we can understand.
- Kansans are often confused and unhappy by the lack of continuity across healthcare settings and among healthcare professionals.
- Healthcare professionals, clergy and citizens all need more information and education.

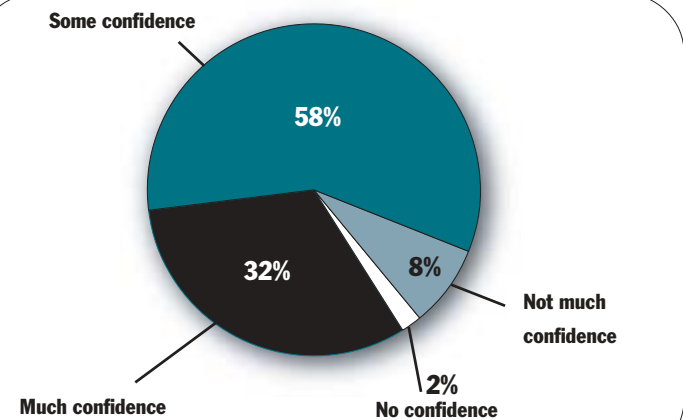
Have you done anything to address the kind of care you will receive if you ever become unable to speak for yourself?



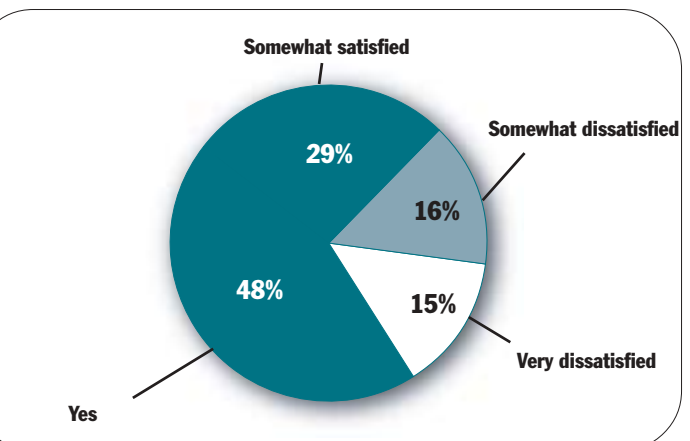
Of those who have completed an advance care directive:

- 43% have completed a living will
- 37% have completed a Durable Power of Attorney for Healthcare Decisions

How confident are you that you, and those you love, will be able to live well as you near the end of life?



If you have experienced significant pain, have you been satisfied with the way your pain has been managed?



“I want the truth. Don’t pad it. Just tell it like it is. And if you don’t know, just tell me that you don’t know.”

—Kansas
Town Hall
Participant



“If you don’t have someone to fight for you, you are in trouble.”

—Kansas Town Hall
Participant

“The most difficult barrier of all is just facing death itself. We want to feel invincible.”

—Kansas
Town Hall
Participant

A National Perspective on Family Satisfaction with End-of-life Care

Family Satisfaction Levels in Five Key Areas:

The health care system:	TOTAL%	PATIENT’S LAST PLACE OF CARE			
		Home Care	Hospice	Nursing Home	Hospital
1) Provided desired physical comfort and emotional support to patient					
Patient did not receive any or enough help with					
Pain	24.2	42.6	18.3	31.8	19.3
Dyspnea	22.4	38.0	25.6	23.7	18.9
Emotional Support	50.2	70.0	34.6	56.2	51.7
2) Supported shared decision making					
Respondent wanted but did not have contact with physician	30.1	22.5	14.0	31.3	51.3
Respondents with contact had concern(s) about physician communication	23.9	26.6	17.6	17.7	27.0
3) Treated patient with respect					
Not always treating patient with respect	21.1	2.9	3.8	31.8	20.4
4) Attended to needs of the family					
Concern(s) about emotional support	34.6	45.4	21.1	36.4	38.4
Concern(s) about information regarding what to expect while patient was dying	29.2	31.5	29.2	44.3	50.0
5) Coordinated care					
Staff did not know enough about patient’s medical history to provide best care	15.2	7.5	7.9	19.6	15.4
Overall Assessment of Quality of Care as Excellent	49.4	46.5	70.7	41.6	46.8

—Study by Joan Teno, et al. JAMA, January 7, 2004, Vol. 291, No. 1, pp. 88-93.

The research was gathered using a mortality follow-back survey of family members or other knowledgeable informants representing 1578 decedents, with a 2-stage probability sample used to estimate end-of-life care outcomes for 1.97 million deaths from chronic illness in the United States in 2000.

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

Key Challenges and Issues to Address As We Plan for Action to Achieve Excellence in Care for Kansans Living with Chronic and Terminal Illnesses

Pain and Symptom Management

- What actions might support our continuing efforts to improve pain management?

Having Patient Wishes Known and Honored

- How do citizens and healthcare providers better develop a culture and systems that honor and encourage these conversations?
- How do we provide better information and education that more fully and effectively engages patients and families in decision-making processes?

Truth Telling, Communication and Respect

- How do we more fully discuss and disclose information about health and illness to Kansans?
- How do we more fully discuss and explore benefits and burdens and the costs and rewards of specific medical interventions?

Palliative Care

- How do we more fully understand, provide and integrate palliative care as a truly interdisciplinary practice?

Respect and Presence

- How do we develop the practice of “being with” and of respecting all patients in ways that convey that respect to them and their families?

For each of these areas

- What are the key barriers to excellence?
- What are the roles and responsibilities of Kansas healthcare professionals?
- What are the roles and responsibilities of Kansas citizens?
- What are the roles and responsibilities of Kansas public policy leaders?
- How do we better develop a culture and systems that address these issues and challenges?

Moving Forward

The Movement to Excellence in Care for Kansans with Advanced Chronic and Terminal Illnesses Requires Movement

- Moving from a disease and treatment centered approach to a patient and family centered approach
- Moving from curative *or* palliative care to curative *and* palliative care
- Moving from a medicalized model to a humanized model
- Moving from a compartmentalized approach to a holistic approach
- Moving from denial and abandonment to presence and care
- Moving from prescriptive approaches to consultative approaches

LIVING INITIATIVES FOR END-OF-LIFE CARE

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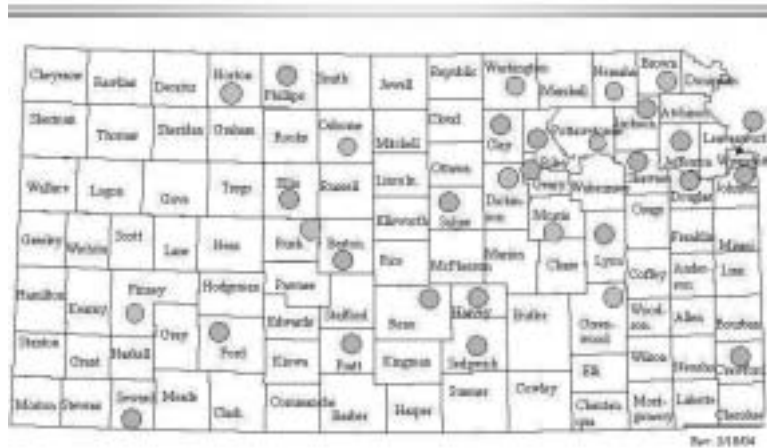
The LIFE Project addresses public policy, professional education, and public engagement. Visit our website at www.lifeproject.org or call us at (888) 202-LIFE (5433) or, in Wichita, at (316) 219-3059.

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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 Caring Communities



Together, We Are Making a Difference

LIFE Project Partners:

Consumer Advocacy Groups: Kansas Advocacy & Protective Services • Kansas Advocates for Better Care • AARP Kansas • **Professional Associations:** Kansas Association for Family & Community Education • Kansas Association of Osteopathic Medicine • Kansas Chapter NASW • 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 • Kansas Association of Homes & Services for the Aging • **Educational Institutions:** Center on Aging at KUMC • Emporia State University • Johnson County Community College • KSU Extension – Research Services • KU School of Medicine • KU School of Nursing • Wichita State University **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 • Kansas Insurance Department • Kansas State Board of Healing Arts • Kansas State Board of Nursing • Kansas State Board of Pharmacy • Kansas State Long Term Care Ombudsman • Office of the Governor • Office of the Attorney General • State of Kansas Library • **Medical Providers:** Harry Hynes Memorial Hospice • KU Medical Center, Kansas City • Shawnee Mission Medical Center • Via Christi Regional Medical Center, Wichita • Wesley Medical Center, Wichita • **Media:** Kansas Association of Broadcasters • Kansas Press Association • Kansas Public Television • KOOD-TV • KPTS-TV • KTWU-TV • Kansas Senior Press Services • **Other Partners:** American Cancer Society-Heartland Division • Center for Practical Bioethics • Foundation for Hospice Care, Inc. • Kansas Health Ethics • Kansas Health Institute • Kansas Humanities Council • Kansas League of Women Voters **Caring Communities:** Clay Center, Dickinson County, Dodge City, Emporia, Garden City, Great Bend, Greenwood County, Hays, Holton, Hutchinson, Jackson County, Junction City, Kansas City, Lawrence, Liberal, Manhattan, Morris County, Nemaha County, Newton, Northeast Kansas, Norton, Osborne County, Oskaloosa, Phillipsburg, Pittsburg, Pratt, Rush County, Salina, Shawnee Mission, Topeka, Wamego/Pottawatomie County, Washington County, Wichita