



Why should Kansas public policy leaders be interested in improved end-of-life care?

LIFE Project partners have learned that end-of-life care needs focused and sustained attention. The needs cut across the entire health care system and are visible in every spectrum of care.

- Medical professionals are not typically trained to deal with issues that emerge at the end of life.
- Health care systems are not structured to deal with patients who are dying.
- Citizens do not have a clear understanding of the choices in care at the end of life.
- Public policy has not always considered the needs of citizens at the end of life.

“Death is not an optional event. It is a shared human experience. Living our last days with meaning and purpose, free of pain, involved in our own health care choices, unburdened of overwhelming financial concerns and knowing our loved ones will be supported is a right every Kansan can and should reclaim.”

— Donna Bales, LIFE Project Director

Far too many people suffer needlessly. Barriers and challenges abound. During the decade of the 90’s, numerous studies helped to create awareness of the great needs for improvement in care for those at the end of life. A brief summary of a few of these studies reveals the depth and breath of the issues we face.

- Education and training for health care professionals fails to provide them with appropriate attitudes, knowledge and skills require to care well for dying patients.¹
 - Economic, legal, and organizational obstacles get in the way of offering excellent care at the end of life.¹
 - 40% of patients end their lives in moderate to severe pain.²
 - 50% of patients report that their own wishes for care are not known by their caregivers.²
 - 38% of patients spend over 10 days in intensive care, receiving aggressive treatment at the end of life.²
 - Even with hospitalization insurance, nearly 1/3 of all families caring for those at the end of life lose most or all of the family savings.²
 - Nearly 50% of patients at the end of life are fed by tube, ventilated on a machine, or given a try at resuscitation.³
 - In 1994, only 5 out of 125 medical school textbooks included end-of-life care.
 - 56% of oncologists report difficulty

in finding palliative (comfort) care consultation. (10 times that reported by Canadian and British physicians).⁴

- Most people who have advance care directives have not told their caregivers about them; and most are too vague to be helpful.⁵
- Citizens do not talk about their wishes for end-of-life care and do not understand their choices.⁶

The LIFE Project partners have learned more about how Kansans feel about end of life. In 1999, we held focus groups where citizens shared with us about their hopes, thoughts and fears about end-of-life care. We learned that:

- Kansans want to die at their own home with family and friends.
- Kansans fear reaching the end of life hooked up to machines.
- Kansans do not believe the current health care system supports their wishes.
- Kansans believe that it is important to plan for death and dying – but are not doing this planning.

“I want people to care what happens to me. I want quality care at the end of life, with no pain, and a willingness to do what I want. I think that's what everyone wants: A peaceful death, as painless as possible.”

—Emily Taylor, *Lawrence Journal-World*, 2/28/00

- Kansas express concerns that they do not know how to have meaningful conversations with those they love about their wishes at the end of life.
- Kansans say that family considerations are of primary concern to them.
- Kansans say they do not understand advance care directives and are confused about what they really mean.⁷

What initiatives will the LIFE Project implement?

To address the needs, the LIFE Project partners named task groups for three strategic areas: Public Policy, Public Engagement and Professional Education. The LIFE Project believes that:

An environment of strength and health in

public policy supporting quality care at the end of life

+
Engaged and empowered citizens
+
Expertise and competence in health care systems and health care professionals
=
Excellence in end-of-life care

Each task group is already actively involved in major efforts.

Public Policy

The Public Policy Task Group named a work group to focus on examining advance care planning. LIFE Project partners discovered that there are a variety of practices in Kansas related to advance care planning. The group is working to identify best practices in advance care planning. The group will determine if there are any public policy barriers to implementation of these best practices. If barriers are identified, solutions will be sought. Educational efforts to strengthen provider and consumer use of best practices will be planned.

The Public Policy Task Group is planning a “Regulatory Summit” that will convene professional leaders to focus on improved end-of-life care. Public policy leaders will be encouraged to voice clear support and encouragement for quality end-of-life care.

The Public Policy Task Group has engaged in conversation, dialogue and action with public policy leaders who bring great insight and support. The group will continue to work with these leaders.

Public Engagement

The Public Engagement Task Group has gathered leaders from over 15 Kansas communities that have called together groups of community leaders who will work to improve end-of-life care in their own locales. These *Caring Communities* serve as the grass roots arm of the LIFE Project -- keeping the project informed about Kansans and their concerns and keeping Kansans informed about issues related to end-of-life care.

The major focus of the *Caring Communities* in 2000 will be involving communities in watching, discussing, and learning from a four-part Bill

did you know?

- Over 23,000 Kansans die each year
- About 80% do not die suddenly
- About 50% die in hospitals
- About 17% die at home
- About 28% die in long-term care facilities
- About 5% die elsewhere

—Kansas Annual Summary of Vital Statistics, 1997

Moyers’ series, *On Our Own Terms*. The series is a major exploration of end-of-life care. Public television leaders and LIFE staff and the *Caring Communities* will create and utilize opportunities for community dialogue and learning.

Each *Caring Community* sent leaders to a training/planning retreat, has developed a local leadership council and is networked with other *Caring Communities*.

The Public Engagement Task Group is working on numerous activities intended to get information into the hands of Kansans. Plans include:

- Creation and distribution of a wall chart on pertinent issues related to end of life. These wall charts will be displayed in health care provider locations, libraries, pharmacies, churches and senior centers.
- Creation of a consumer materials on end-of-life care.
- Creation of a website and toll-free number for Kansas citizens to access further information about end-of-life care.
- A major media campaign to create public awareness and offer information about end-of-life care.
- Sharing of information at special community events in Kansas.



Professional Education

The Professional Education Task Group will:

- Offer the American Medical Association's Education for Physician Education on End-of-Life Care (EPEC) to Kansas health care professionals via 2-day intensive classes and via teleconference.
- Conduct a pilot project at Central Kansas Medical Center in Great Bend. The project will focus on quality palliative (comfort) care and advance care planning.
- Survey pain assessment and management practices in Kansas health care facilities and engage leaders in creation of best practices.
- Publish a pain management hotline for Kansas physicians.
- Sponsor "Stories at Work," with the Kansas Humanities Council, to explore attitudes and values that impact end-of-life care.
- Sponsor training in Palliative Care for physicians, nurses and pharmacists, featuring Dr. Robert Twycross, Director, World Health Organization Collaborating Center for Palliative Care.
- Publish a weekly electronic update on end-of-life issues.
- Publish a monthly electronic *LIFeline* on the work of the LIFE Project.

What may Kansans expect? What are the hopes and goals of the LIFE Project?

The good news for all Kansans is that Kansas citizens, public leaders, health care professionals, and policy leaders are all working together to address issues that impact end-of-life care. Our mission is to **work to improve end-of-life care for all Kansans.** LIFE Project partners hope for these results:

- Kansans will live in a state where public policy, legislation and regulation support and encourage quality care at the end of life for all citizens.
- Citizens will have more information about end-of-life care, have higher expectations for the quality of care at the end of life, and become better advocates for that care.
- Kansans will expect and receive excellent pain and symptom management.
- Communities and employers will have a better understanding of the importance of end of life
- Kansas health care professionals will be well informed about end-of-life care.

- Those who pay for care will be willing to reimburse for palliative (comfort) care.
- Health care systems will be structured to support and offer quality care to those at the end of life.

Much has been accomplished since the many diverse organizations created the LIFE Project. Much remains to be done. With the current spirit of cooperation and a growing weight of importance being placed on end-of-life issues, Kansans should have high expectation of improved care at the end of life.

References:

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6. Quest to Die with Dignity: American Health Decisions, 1997
7. Kansas focus groups led by Diane Felt, 1999

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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* will address three questions:

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

"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

Project planning?

- What may Kansans expect?

LIFE Project partners include:

AARP of Kansas • Association of Kansas Hospices • Center on Aging at KUMC • Central Kansas Medical Center, Great Bend • Kansas Advocacy & Protective Services • Kansas Advocates for Better Care • Kansas Association for Family & Community Education • Kansas Association of Broadcasters • Kansas Association of Osteopathic Medicine • Kansas Board of Emergency Services • Kansas Cancer Pain Initiative • Kansas Department of Health & Environment • Kansas Department on Aging • Kansas Foundation for Medical Care • Kansas Funeral Directors & Embalmers Association • Kansas Health Care Association, Inc. • Kansas Health Ethics • Kansas Health Institute • Kansas Home Care Association • Kansas Hospital Association • Kansas Humanities Council • Kansas Insurance Department • Kansas Medical Society • Kansas Organization of Nurse Leaders • Kansas Pharmacists Association • Kansas Public Television • KOOD-TV • KPTS-TV • KTU-TV • Kansas State Board of Healing Arts • Kansas State Board of Nursing • Kansas State Board of Pharmacy • Kansas State Long Term Care Ombudsman • Kansas State Nurses Association • KS Association of Homes & Services for the Aging • KS Chapter NASW • KS Chapter League of Women Voters • KS Department of Social & Rehabilitation Services • KS Senior Press Services • KSU Extension - Research Services • KU Medical Center • KU School of Nursing • Midwest Bioethics Center • Office of the Governor • State of Kansas Library • Via Christi Regional Medical Center

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