



Living Initiatives For End-Of-Life Care

Helping all Kansans live with dignity, comfort and peace at the end of life

1998 – 2002 The First Five Years

The LIFE Project Foundation, Living Initiatives For End-of-Life Care, is a collaborative effort of over 70 organizations statewide. The mission of the LIFE Project is to help Kansans live with dignity, comfort and peace at the end of life. The LIFE Project has achieved national recognition for improving end-of-life care at the state level.

LIFE Project Partners include Governmental Agencies, Medical Providers, Academic Institutions, Professional Associations, Media Organizations, Consumer Advocacy Groups, *Caring Communities* (LIFE Project's locally-based advocacy and workgroups) and others. Many of these Partners share the concern for Caregivers, as their letters of support indicate. These Partners bring expertise and shared concern to the issue and have proven their ability to partner together in effective ways.

Though there is much to be done to improve end-of-life care, Kansans are fortunate to have a group of partnered organizations working actively to address issues that impact quality care that helps Kansans live with dignity, comfort and peace as they near the end of life. Current initiatives address advance care planning, improved pain management, consumer activism, professional education and support for excellence in public policy.

The LIFE Project has numerous strategic interventions designed to improve life for Kansans nearing the end of life. As a result of creative interventions, the LIFE Project has, in just three years of active engagement:

- * Created a **network of collaborative agencies, initiatives and activities** of over 70 organizations statewide;
- * Built a **network of more than twenty community-based advisory/leadership groups called *Caring Communities***;
- * Presented **educational events and speakers** for physicians, nurses, long-term care facilities and acute care facilities;
- * Brokered a **Pain Protocol Project** that is addressing systemic change in acute and long-term healthcare providers' practices;
- * **Addressed public policy issues** including end-of-life care, advance care planning, pain management and guardianship;
- * **Developed a public awareness campaign**, supported by the Kansas Association of Broadcasters, about the issues facing Kansans nearing the end of life;
- * **Convened and participated in policy briefings** and planning meetings;
- * **Launched a website** that offers ongoing communications for the public of Kansas and for Project Partners (www.lifeproject.org);

* **Staffed a consumer-information toll-free Helpline, promoted a statewide pain management hotline, and served as a communication hub** for information on end-of-life care via meetings, communiqués, and weekly and monthly newsletters;

* **Managed a bi-state telehospice project** exploring the use of technological interventions that help both urban and rural Kansans remain in their own homes and communities as they near the end of life;

* **Facilitated statewide networking of PBS in end-of-life broadcasting**, and, most importantly,

* **Served as advocates for all Kansans, their families and friends as they near the end of life.**

LIFE Project Timeline

1998-99:

The LIFE Project, convened by Association of Kansas Hospices, held its first meeting on 2/13/98. Participants were briefed on critical issues in end-of life care and invited to join together in identifying and addressing issues related to care for Kansans as they near the end of life.

The participants, and others who joined the Project as it developed, met each month and worked together in learning, sharing and planning to address critical issues related to end of life.

After months of deliberation, the participants identified three major areas to address-- public policy, professional education and public engagement

Project Partners agreed on principles for palliative care, pain management and advance care planning.

Participants volunteered to work on specific initiatives and address the major areas of concern.

2000, 2001, 2002:

Public Policy:

Reviewed all statutes and regulations and determined to address advance care planning and guardianship, 2000.

Committed to following legislative and regulatory developments that impact end-of-life care, 2000-2002.

Sought help from Kansas Health Care Data Governing Board in getting basic data on end-of-life care in Kansas, 2000.

Convened licensing boards and key leaders and called for joint pain management guidelines and visible commitment to excellence in pain management, 2001-2002.

Offered ongoing expert testimony to key leaders including Senate and House committees on Public Health and Welfare, Legislative committees on Futures and on Long-term care.

Positioned Project to identify and learn from models that address reimbursement for end-of-life care.

Design for Change, Issue I, written to highlight the issues and the plans, 2000.

Continued to maintain a collaborative approach to improving end-of-life care for all Kansans and maximize the resources of the LIFE Project Partners in addressing this goal, 2000-2002.

Professional Education:

Provided training for a cadre of health care professionals from across the state.

Used AMA's EPEC, offered in two-day intensive courses, in training health care teams from all across Kansas. Offered in spring 2000, 2001 and 2002.

Offered a weeklong training on palliative care, led by an international team of experts, 2000.

Offered ELNEC, end-of-life care training for nurses, 2002.

Offered EPEC course via teleconference, 2001.

Addressed systemic issues in improving pain management via creation and oversight of a Pain Protocol Project, working with Kansas hospital and long-term care facilities, 2000-2001.

Offered educational speakers to Project Partner meetings, community groups and others, 2000-2002.

Impacted attitudinal barriers to quality end-of-life care by creating and publicizing "Stories at Work" with Kansas Humanities Council, 2000-2002.

Worked with educational institutions to encourage improved focus on end-of-life care, 2000-2002.

Implemented a tele-hospice project focused on improving service to hospice patients by adding additional resources, 2000-2002.

Public Engagement:

Created and supported locally-based community councils, *Caring Communities*, to identify and address issues related to end-of-life care, 2000-2002.

Created and utilized resources and information about end-of-life care for Kansas citizens, 2000-2002.

Worked with Kansas State University's Research and Extension to create and utilize consumer materials on end-of-life care, 2000-2002.

Worked with KU Center on Aging and Kansas Department of Aging to create and distribute a wall chart on end-of-life care. Translate the wall chart into a brochure written in Spanish, 2000-2002.

Worked with Kansas Association of Broadcasters in creating and airing of major media campaigns to engage and activate Kansans about end-of-life issues, 2000-2002.

Worked with Kansas PBS affiliates to maximize opportunities for an extensive community engagement campaign utilizing the Bill Moyers' four-part PBS series on end-of-life care, entitled "On Our Own Terms." The series aired in fall 2000.

Developed and coordinated an extensive community engagement campaign maximizing the 15-part newspaper series "Finding Our Way" in the fall of 2001.

Developed and managed an extensive community engagement campaign entitled "Advance Care Planning: *Do it for those you love!*" The campaign included PSAs, written materials, web-based resources, consumer engagement video and speakers bureau. 2001-2002.

Implemented an extensive community engagement campaign entitled "Every Kansan Should Expect Good Pain Management." The campaign includes PSAs, written materials, web-based resources, consumer education video and speakers bureau. 2002.

Offered ongoing leadership as a national role model for consumer engagement efforts to improve end-of-life care.

In addition to these three major foci, the LIFE Project has created and continues to sustain an infrastructure to support the development of networking and collaborative efforts. This infrastructure addresses improved public policy, professional education and public engagement and includes:

Creation and distribution of ongoing communications tools including:

Weekly *Network Newsflash*, which offers a brief summary of what the media said the previous week about end-of-life issues, 2000-2002.

Monthly *LIFeline*, which highlights efforts of the LIFE Project, the Project Partners and *Caring Communities*, 2000-2002.

Frequent one-page briefs on issues of importance, 2000-2002.

Communiqués to *Caring Communities*, 2000-2002.

Creation and oversight of inclusive work groups convened to address specific issues, oversee specific initiatives and plan for special activities, 2000-2002.

Planning and implementation of regular meetings of *Caring Communities* and LIFE Project Partners, 2000-2002.

Promotion of active participation in numerous efforts whose missions intersect with that of the LIFE Project, 2000-2002.

Creation and ongoing development of a virtual community via the ongoing presence of a website, 2000-2002.

Creation and staffing of a toll-free help line, 2000-2002.

Creation and staffing of a pain management hotline, 2000-2002.

Creation of consumer information presentations posted for use by Project Partner leaders, 2000-2002.