

# A Design for Change

ISSUE NO. 2

END OF LIFE CARE ISSUES IN KANSAS



## *Advance Care Planning*

### Do It for Those You Love

Advance Care Planning is a process rather than a document. The LIFE Project encourages all Kansans to:

***Think...*** about the kind of care you would want to receive if you should ever become unable to speak for yourself.

***Talk...*** with those you love about your values, choices and wishes in care.

***Act...*** by completing and signing a Durable Power of Attorney for Health Care Decisions (DPOAHC). Share a copy of this document with your family, health care agent, physician, and, if you have one, attorney.

The LIFE Project believes that the verbal and written advance care plans of all Kansans should be honored. This includes health care treatment directives and Durable Powers of Attorney for Health Care Decisions. The LIFE Project Principles of Advance Care Planning recognize the right of all Kansans to have their wishes honored.



### *Will advance care planning really help those I love?*

YES! Just look at the results of a study by Oregon Health Sciences University published in Nursing Research, March/April 2001:

- Those who participate in advance care planning create a situation that leaves their families with much less stress.
- When advance care plans are both verbal and written, stress levels lower even further.
- Families that participate in advance care planning suffer less guilt and are less “haunted” by their decisions.
- Advance care planning can help you determine the care you receive and improve the difficult end-of-life experiences for your family.

*Talking about and writing down your wishes so that your family members have a clear guide to follow near the end of life will reduce the stress on those you love.*

*Planning in advance, free of crisis and pressure, is the best way to make sure that you receive the health care you want at the end of life. The decisions and thinking that you participate in and share with others while you are healthy will likely be better than decisions that others make for you if you are seriously ill.*

# Advance Care Planning

## Do It for Those You Love

Planning takes time. We spend time planning for our moves, for our children, for our jobs, for our finances and for almost every aspect of our lives.

We spend hours, for example, planning a vacation. We study tour guides, talk to others who have visited the location, plan our itineraries and work carefully to create the experience we want.

Kansans have told the LIFE Project, in focus groups across the state, that we think it is important to plan for the kind of care we want at the end of life or if we should ever become unable to speak for ourselves. But few of



*“I told Mom and Dad that I knew what I wanted for Christmas. I wanted them to tell me about the kind of care they wanted if they should ever become unable to speak for themselves. Knowing that I could honor their wishes was a great gift to me.”*

—Adult son of Kansas parents

us take the time to do this thinking, sharing and planning. And even those who do plan often fail to talk about their wishes with those they love. It is important that

Families who have talked about their wishes for care most often have less stress and guilt through such a crisis than those who have not.

both this talking and planning happen.

Americans are living longer and dying differently. For the first time in human history there are many choices about when, where, and how a person will die. These choices are the result of dramatic changes in medical science and technology.

It is difficult to face the reality that someone you love is dying and unable to speak for himself or herself. Much of the stress is unavoidable.

### Fact:

**Four out of five Kansans will not die suddenly. When Kansans are unable to tell us what kind of care they want to receive:**

- \* **Families face tremendous stresses.**
- \* **Critical decisions must be made.**
- \* **Emotions run high.**
- \* **Conflicts between family members often emerge.**

*The way that Americans live and die has changed dramatically in the last century. The chart below illustrates some of these changes.*

|                           |                                   |   |
|---------------------------|-----------------------------------|---|
| Age at Death              | 46                                | 78  |
| Leading Cause             | infection, accident<br>childbirth | cancer, heart disease,<br>stroke/dementia |
| Place of Death            | home                              | hospital                                  |
| Most Medical Expenses     | paid by family                    | paid by Medicare                          |
| End-of-Life Interventions | little done                       | high technology                           |
| End-of-Life Expenses      | minimal                           | very high (1/3<br>spend life savings)     |
| Disability before Death   | not usually                       | more than 4 years                         |

# Advance Care Planning

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## Do It for Those You Love

*Think....about the kind of care you want to receive.*

- Would you want treatments that might prolong your life if you were no longer able to care for yourself? Unconscious and not likely to regain consciousness? Terminally ill or near death?
  - How do you feel about relying on machines in order to stay alive?
  - Do you want everything possible to be done to delay death?
  - How do you feel about enduring pain and suffering at the end of life? Would you want to be sedated if it were necessary to control your pain?
    - If you could no longer swallow, would you want tube feedings?
    - Would you want to have a hospice or palliative care team available to you?
    - Would you prefer to die at home or in a health care facility?
    - Is there someone you trust enough to make your health care decisions for you? Is that person willing and able to take on this responsibility?

*Talk....with those you love and who care for you about the kind of care you hope to receive.*

- You might start the conversation by sharing about someone else's experience, saying your attorney asked you to work on it, or writing a letter. See the LIFE Project website ([www.LIFEProject.org](http://www.LIFEProject.org)) for ideas about beginning the conversation.

- Several LIFE Project Partners have resources that may help you. These Partners are available through our website. The website also includes a list of guides and handbooks that may be helpful to you.
  - Talk with those you love about your answers to the questions listed and share your hopes and wishes for care.
  - Talk with your physician about your wishes and make sure that your doctor is willing to follow your directions.
  - Know that it is common to have resistance and fear about having these conversations.

*Act....by completing a Durable Power of Attorney for Health Care Decisions and sharing a copy with your family, physician, health care agent and attorney.*

- Complete a Durable Power of Attorney for Health Care Decisions, available at: [www.LIFEProject.org/\\_cr\\_ad.htm](http://www.LIFEProject.org/_cr_ad.htm)
  - Name an agent who knows you, understands your choices and values, and is willing and able to carry out your wishes.
  - Share copies with your family, physician, health care agent, attorney and others.

*The LIFE Project encourages the completion of a Durable Power of Attorney for Health Care Decisions. It will be used whenever you become unable to speak for yourself. The health care agent may make decisions based on knowing you and your wishes and on knowing the situation you face.*

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

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# LIVING INITIATIVES FOR END-OF-LIFE CARE

**The LIFE Project works to help Kansans live with dignity, comfort and peace at the end of life.**

The LIFE Project addresses public policy, professional education, and public engagement. Visit our website



at [www.LIFEProject.org](http://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 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.**



LIVING INITIATIVES FOR END-OF-LIFE CARE

1901 University Avenue, Wichita, KS 67213



## LIFE Project Partners:

**Consumer Advocacy Groups:** Kansas Advocacy & Protective Services • Kansas Advocates for Better Care • AARP of Kansas • **Professional Associations:** Association of Kansas Hospices • 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 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 • KSU Extension – Research Services • KU School of Medicine • KU School of Nursing • **Governmental Agencies:** 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 • State of Kansas Library • **Medical Providers:** Central Kansas Medical Center, Great Bend • Hospice Inc., Wichita • 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:** Kansas Health Ethics • Kansas Health Institute • Kansas Humanities Council • Kansas League of Women Voters • Midwest Bioethics Center • **Caring Communities:** Clay Center, Dodge City, Emporia, Great Bend, Hays, Holton, Hutchinson, Junction City, Kansas City, Lawrence, Liberal, Manhattan, Newton, Oskaloosa, Phillipsburg, Pittsburg, Pratt, Salina, Shawnee Mission, Topeka, Wichita