



*When we enter this world, we are surrounded by love, comfort and care. Do we not deserve the same when we leave?*

Death is not an optional event. Over 23,000 Kansans die each year. Yet very few of us have talked with our loved ones or our health care provider about our wishes for end-of-life care. We all say that we want to have a good death, yet it is difficult for that to happen if no one knows what our conception of a “good death” is. Although talking about, and documenting our choices for end-of-life care may be difficult, it also one of the most important steps we can take toward the goal of dying well.

# End of Life:

## Kansans Deserve Excellent Care

### Introduction

The overwhelming majority of people say that if they had a terminal illness, they would prefer to die in their own homes, surrounded by loved ones. Yet that is not how most of us die. Statistics reveal that most people spend their final days in institutional settings, such as hospitals and nursing homes. And despite the fact that modern medicine makes a pain-free death a possibility for almost everyone, research shows that many people die in pain. Why is it that what we want, and what we deserve, are so far out of step with what we get?

Experts point to three main issues when addressing this question. First and foremost, we are part of a youth-worshipping culture that denies death. We avoid discussing this topic with our family members. We neglect talking to our doctors about our preferences for end-of-life care. We put off documenting our preferences even though we say it is important to do so. Results of a Gallup Poll showed that 75% of Americans want to have a Living Will, but only 20% say they have written one.

Second, our health-care professionals typically receive little or no training in caring for a dying person. About two-thirds of physicians responding to a survey of Sedgwick County Medical Society members, reported they were inadequately trained in pain management.

Finally, our public policies related to health care often do not support people’s end of life preferences. Although home-based services are typically preferred by individuals and are usually much less expensive than hospital or nursing home services, they are often hard to find, arrange, and may not be covered by insurance or public assistance.

End-of-life experts suggest that our society needs the following in order for people’s preferences surrounding end of life care to be achievable:

- Medical professionals with expertise in end-of-life care;
- Public policy that supports the end-of-life care preferences of our citizenry;
- A well-informed public that is not only aware of its options for end-of-life care, but takes steps to ensure that its preferences are understood and honored.

## Advance Directives

Your end-of-life care wishes can be documented in written instructions called “advance directives.” Advance directives include documents such as the Durable Power of Attorney for Health Care Decisions, Living Will, and Do Not Resuscitate Order. These documents allow you to communicate your wishes when you do not have the capacity to do so yourself. To obtain copies of advance directive forms and accompanying instructions, check with your physician, local Extension office, local hospital, or county health department. Kansas specific advance directives can also be download from the following web sites:

[www.kansashealthethics.org](http://www.kansashealthethics.org),  
and  
[www.partnershipforcaring.org](http://www.partnershipforcaring.org).

Follow the instructions carefully to make sure you complete the forms correctly and have them witnessed or notarized properly. Copies of your advance directives should be given to your loved ones, health-care providers and other important people (e.g. friends, clergy, lawyer).

## Why Talk About It?

Unless you have talked with your loved ones and health-care providers about your wishes for end-of-life care, they will not know how you want to be treated. There may be medical treatments that you would want to have if you were dying. Alternatively, there may be interventions that you don’t want. If you have conversations now about these topics, while you are still able to do so, you will not only help to see that your preferences are honored, but you will give a great gift to your loved ones. The peace of mind that comes from being able to honor a loved-one’s wishes is invaluable. While you may feel threatened by the prospect of talking about death, you may find that the actual process of having conversations with your loved ones is reassuring and eases your fears about the end of life.

## Planning Ahead

Planning for any major event is useful. Death is not an exception to this rule. By being prepared for your death, it is more likely that your preferences for end-of-life care will be honored. One should keep in mind that the end of life does not have to be a wretched event. On the contrary, it can be a valuable time of serenity and growth that unites family members in their shared love. The chance that this will be true is more likely if you have planned ahead. Some steps you might take to be prepared for the end of life are:

- Clarify your own values related to end-of-life issues. For example, do you hold spiritual beliefs that influence the way you view death and dying?
- Learn about your options for end-of-life care. For example, find out about hospice care and other options available to people who are dying.
- Have conversations with your loved ones about your values and preferences for end-of-life care. Do not expect to talk just once and have everything settled; keep the discussion going.
- Talk to your health care providers about the type of care you want at the end of life.
- Document your wishes by completing forms called “advance directives,” such as the Living Will and Durable Power of Attorney for health care decisions (see side bar).
- Engage in financial planning. Some issues to consider are: health insurance, long-term care insurance, life insurance, wills, letter of last instructions, trusts, gifts and annuities. For information on insurance issues, contact the Kansas Insurance Department for its free publications (1-800-432-2484). For estate planning information, obtain the following five-part series from your county extension office: *Estate Planning: The Basics* (L849 - L853).

## Insist on Good Pain Control

A big fear of many people is a lingering, painful death. Thanks to modern medicine, dying in pain is largely unnecessary. Doctors can provide strong painkillers and manage their side effects so that patients remain both alert and pain free at the end-of-life. In order to get adequate pain control, families must often serve as advocates for their loved ones. There is an unfortunate association of painkillers with illegal drugs and addiction. But addiction is simply not an issue when medication is given for pain. As a patient or family member, you should insist on good pain control and work with your health care providers until it is achieved. Serving as an advocate for a loved one is not only valuable in terms of pain control, but is important in every step of end-of-life treatment.

## Opening Conversations

Figuring out how to open a conversation about the end of life is not an easy task. Some of the following tips may be helpful:

- Use a personal event, such as the illness or death of a friend or relative, to broach the subject. For example, you might raise questions such as: “Did you know that John is under hospice care?,” or “Did you know that Jane died without a will”?
- Use a public event, such as a news story or television show on end-of-life issues, to raise the topic. Public Television is broadcasting a 4-part series on end-of-life issues in September, 2000, entitled *ON OUR OWN TERMS* in a videotape of this series. Ask your Family and Consumer Science agent about how you can obtain a videotape of this series.
- Talk about your own plans and wishes for end-of-life care first before expecting others to do so. For example, an adult child might say: “Mom, did you know that I have filled out a Living Will”?
- Take advantage of openers that others offer you. For example, if a family member who is seriously ill mentions that they are not doing well, take the opportunity to follow-up on their concerns.

## Making Your Wishes Known

Talking about death and dying is often difficult. To make the process easier, Midwest Bioethics Center in Kansas City (1-800-344-3829; [www.midbio.org](http://www.midbio.org)) provides a workbook to help you have “caring conversations” with your loved ones. This workbook offers a series of questions to help you think about your future, make decisions and communicate them to your loved ones. When you are having these conversations with your loved ones, you don’t have to focus solely on death. According to Joanne Lynn, M.D., of Americans for Better Care of the Dying, it is important to remember that you and your loved ones all have a past, present and future, and it can be helpful to reminisce and share stories from the past as well as talk about future dreams and plans. Questions to help you have “caring conversations” include:

- With whom do you want to have these conversations?
- What do you most want to say to them?
- What beliefs do you hold that influence your thoughts about life and your thinking about dying?
- What concerns do you have about your health or future health care?
- What are your fears regarding the end of your life?
- Are there circumstances under which you would refuse or discontinue treatment that might prolong your life?
- If you could plan it today, what would the last day of your life be like?
- Are there people to whom you want to write a letter or for whom you want to prepare a taped message, perhaps marked for opening at a future time?
- Would you want to make a final trip to visit family, friends, or a special place?
- What are your thoughts about your memorial service?
- What is important for others to know about the spiritual or religious part of your life?
- Who would you want to make health care decisions for you if you could not make them for yourself?

## Feeling at Peace

People who are dying and their family members may feel the need to communicate important messages to each other but may not know how to start. Palliative care expert, Ira Byock, suggests that communicating the following five messages may help persons who are dying and their loved ones feel at peace:

- I love you
- Forgive me
- I forgive you
- Thank you
- Good-bye

## Enhancing Quality of Life at the End of Life

As mentioned before, death does not have to be a wretched event. Steps can be taken to enhance the quality of life of persons who are dying and their families. In fact, a medical specialty, called “palliative care”, or comfort care, is focused on this goal. When a person is in the last chapter of life, palliative care helps to ease pain and make life better for that person and their loved ones. The goal of palliative care is for those who are dying and their families to have the best quality of life possible. Palliative care not only looks after a person’s medical needs, but also considers the emotional, social and spiritual needs of the person. Ira Byock, a physician and palliative care expert, points out that palliative care is unique among clinical specialties “...in acknowledging that dying is normal - part of the life of every individual and every family.” He adds that “...palliative care strives to promote opportunities for the person and family to grow, individually and together, during this poignant and often precious time of life.”

## One Option: Hospice Care

Hospice care is a form of palliative care that focuses on enhancing the quality of a person’s remaining days. Persons under hospice care and their family members receive an array of services that typically include visits from specially-trained registered nurses, nurse aides, social workers, chaplains, bereavement counselors, and volunteers. Hospice medical care focuses on providing pain relief and managing other symptoms so that the person is as comfortable as possible. But hospice does much more than provide symptom relief. Hospice is a holistic approach to care giving that also addresses the emotional and spiritual needs of the dying person and family members. Hospice care serves anyone with a terminal illness, not simply cancer patients. Hospice care can be provided in many different settings, including private homes, nursing homes, and hospitals.

Hospice care is not for everyone, and nobody should feel pressured to accept hospice care. Even after hospice care has started, individuals are free to change their minds and ask that curative care be reinstated. Hospice services are covered by Medicare when a person is expected to live for six months or less.

Unfortunately, however, families often select hospice care too late for it to be of much help. Indeed, the median length of hospice care is only 25 days. Families are encouraged to consider hospice care at an earlier point in a person’s illness when there is more time to have a positive impact on the lives of patients and their loved ones. For more information on hospice care, contact the Association of Kansas Hospices (316-263-6380) or the National Hospice and Palliative Care Organization ([www.nhpco.org](http://www.nhpco.org); 1-800-854-3402).

## The Question of Tube Feeding

Whether to provide tube feedings and intravenous (IV) fluids to a dying person is a personal issue that deserves careful consideration. Individuals and their family members may find it helpful to discuss this issue with health care providers, social workers and clergy members. When discussing this subject, some issues are worth considering. One is the use of the word “feeding.” Receiving nutrition through a tube is not the same thing as being fed a regular meal. There is no pleasure, and there may be discomfort associated with receiving nutrition through a tube. In addition, there is no evidence that tube feedings and IV fluids make death less painful. In fact, the opposite may be true. According to the *Handbook for Mortals*, “For those who are dying, the time comes when it might be more compassionate, caring, even natural to allow dehydration to occur. Forcing tube feedings and IVs on dying patients can make the last days of their lives more uncomfortable.” Family members may worry that their loved one is thirsty. It is unlikely for a dying person to experience thirst, but a person’s mouth may become dry. If so, moistening the person’s mouth with a sponge or ice chips should provide relief.

Individuals and their family members may be under the mistaken assumption that artificial nutrition and hydration are legal requirements. As the *Handbook for Mortals* points out, no adult is required to accept any medical treatment (unless the disease is a risk to others). Furthermore, stopping artificial nutrition and hydration, even after months or years, does not raise questions of homicide or suicide. Stopping, or not using, these procedures simply allow the disease to follow its natural progression.

## Death as an Important Passage

Our society honors many important passages throughout a person’s life: birthdays, religious initiations, graduations, marriage, having children, retirement and more. But death, at least in recent times, is a passage that is often met with silence and denial. We have taken death out of our homes and our consciousness and pushed it into hospitals and long-term care facilities where dying is often dehumanized and over-medicalized. It is time for us to reclaim death as an important passage and to honor those who are dying with the respect, dignity and excellent care they so deeply deserve. Recent changes in attitudes toward childbirth have given expectant mothers back their autonomy, moving them from isolated, institutional hospital rooms, to homey, inviting birthing suites with loved ones at their sides and choices in treatment procedures. Similar changes in attitudes are needed toward death and dying in order to humanize an event that should be a valued and honored passage.

## Community Awareness Activities

Contact the LIFE Project (1-888-202-LIFE) to see how you can assist the “Caring Communities” initiative, a project to get the citizens of Kansas engaged in talking about end-of-life care.

- Find speakers who can give a presentation on end-of-life care issues in your community
- Initiate conversations within your family on end-of-life care.
- Complete your own advance directives and encourage other to do so as well.

## The LIFE Project

Headed by the Association of Kansas Hospices, the LIFE Project is a coalition of more than 45 organizations working to improve the quality of end-of-life care for all Kansans. The LIFE Project believes that the end of life can be a time of richness, growth and peace. For this to happen, however, physical, emotional, social and spiritual issues must be addressed. For information on the LIFE Project, call 1-888-202-LIFE (toll free) or go to [www.lifeproject.org](http://www.lifeproject.org). The LIFE Project strives to turn the following vision into reality:

- 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, 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;
- Kansans 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.

## A Caregiver's Story

Betsy Smith cared for her mother, Fan, as she was dying from spinal cancer. she and her husband, Chuck, turned the lower level of their home into a private apartment for Fan and contracted with the local hospice agency to provide care. Serving as care giver was a bittersweet experience for Betsy. She had to resign from her much-loved job. Her marriage suffered under the strain of providing round-the-clock care. The physical work of care giving was sometimes unpleasant and often exhausting. But Betsy also had the opportunity to spend treasured time with her mother. In addition, Hospice gave “great physical and emotional support” to their family. Betsy loved how the Hospice nurses and aides would take time to talk to them “as people” and were “never impatient or rushed.” Fan loved chatting with the aides about events in their lives and Betsy felt that these conversations enhanced her mother’s quality of life in a wonderful way. Despite the sacrifices she made, Betsy is glad she cared for her mom. “I wouldn’t have given up this time with her for anything.” She adds that it is probably a good thing that she didn’t know what would be expected of her because there is a lot of ‘nitty-gritty yuckiness.’ It’s not just a noble thing. But you step up and do what needs to be done.”

For information on family care giving, contact:

National Caregivers Association  
1-800-896-3650 or

[www.nfcacares.org](http://www.nfcacares.org)

## Resources

**The Association of Kansas Hospices (AKH)** assists, strengthens, and augments the services of hospices and hospice care across Kansas. AKH can help you find a hospice program locally or anywhere in the United States. Contact AKH at: 1901 University, Wichita, Kansas, 67213  
316-263-6380  
[www.wichitadirect.com/akh](http://www.wichitadirect.com/akh)

**Kansas Health Ethics (KHE)** is devoted to helping all Kansans understand the importance of ethics in health care planning and decision-making. KHE provides consumers with advance directive documents along with information about their use. Contact KHE at:  
5920 E. Central, Suite 206  
Wichita, Kansas 67209  
316-684-1991  
[www.kansashealthethics.org](http://www.kansashealthethics.org).

**Midwest Bioethics Center** is dedicated to integrating ethical considerations into health care decision-making. It offers advance directives, as well as a workbook, *Caring Conversations*, to help families have conversations about end-of-life care. Contact:

Midwest Bioethics  
1021-1025 Jefferson St.  
Kansas City, Missouri 64105  
800-344-3829  
[www.midbio.org](http://www.midbio.org),

### **Partnership for Caring: America's Voices for the Dying**

is a national organization devoted to raising consumer expectations and increasing the demand for excellent care at the end-of-life. It provides a toll-free counseling line (1-800-989-9455). You can download state specific advanced directives from its Web site.  
[www.partnershipforcaring.org](http://www.partnershipforcaring.org)

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