End of Life:

Kansans Deserve Excellent Care

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.

Purpose

The purpose of this lesson is to help participants understand that they have options for end-of-life care and to explain steps they can take to increase the chances that their end-of-life preferences are understood and honored.

Objectives

By the end of this program, participants should be able to:

- Describe the discrepancy between what people typically say they want for end-of-life-care and what typically happens;
- List two reasons why it is important to talk with your loved ones and health-care providers about your wishes for end-of-life care;
- Describe two steps that one can take to plan for end-of-life care;
- List two or three questions that a person might want to discuss with family members about end-of-life care;
- Describe the purpose of palliative care and/or hospice care.

Before the Program

- Review the teaching guide and fact sheet.
- Obtain a copy of the fact sheet for each participant.
- Have available a flip chart, chalkboard or overhead projector to record group responses
- Obtain one copy of a Living Will and Durable Power of Attorney for health care decisions, along with the instructions for completing them. These can be downloaded from www.kansashealthethics.org or www.partnershipforcaring.org (make sure to get Kansas-specific forms). Review the instructions. Optional: Make copies of the documents and instructions for each participant.
- Have a box of tissues handy in case your participants become emotional during the program. Recognize that this topic may be difficult or painful for some people to discuss, particularly if they have lost a loved one recently.
- Optional: Obtain a videotape copy of the public television series, ON OUR OWN TERMS: Moyers on Dying. For help in securing a copy, call the LIFE project (1-888-202-LIFE), your local public television station, or Films for the Humanities and Sciences (1-800-257-5126). Review the series to determine the segments you want to use. Obtain a TV/VCR for your meeting room.
- Optional: Have copies of Extension's five-part estate planning series available for interested participants: *Estate Planning: The Basics* (L849 - L853).

National Resources

Last Acts is a national coalition working to improve care and caring at the end of life. Its goal is to bring death-related issues out in the open and help individuals and organizations pursue better ways to care for the dying. *wwwlastacts.org*

National Hospice and Palliative Care Organization is a national nonprofit organization representing hospice and palliative care programs and professionals. It offers information on hospice and palliative care programs through its toll-free helpline: 1-800-658-8898. *www.nhpco.org*

Americans for the Better Care of the Dying is a nonprofit organization dedicated to social, professional, and policy reform aimed to improve end-of-life care. It can be reached at: 202-530 -9864. *www.abcd-caring.com*

Partnership for Caring: America's Voices for the Dying is a national, nonprofit 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 advance directives from its Web site. *www.partnershipforcaring.org*

- Optional: Order free booklets for your participants from the Kansas Insurance Department (1-800-432-2484) on Medicare Supplement Insurance, Long-Term Care Insurance, or any other insurance issue in which you think participants may be interested.

(Note that this lesson covers a large range of issues and it may be necessary to pick and choose from the following topics to keep your program to a manageable length.

Societal Views on Death and Dying

Discuss the fact that an overwhelming majority of people (about 90%) would prefer to die at home if they had a terminal illness, yet most people (about 75%) die in hospitals and nursing homes. Mention that despite the fact that modern medicine makes a pain-free death a possibility for almost everyone, research shows that many people die in pain.

Get participants to list the reasons why they think this is true. Record participants' responses on the writing surface you have chosen to use (flip chart, chalk board, or transparency). If necessary, prompt participants to consider the following reasons:

- 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. Point out that the results of a Gallup Poll showed that 75% of Americans say they want to have a living will, but only 20% say they have written one.

- Our health care professionals typically receive little or no training in caring for a dying person. Note that a study in Sedgwick County showed that about two-thirds of physicians feel they are inadequately trained in pain management.

- Our public policies related to health care often don't support people's end-of-life preferences.

Get participants to list some of the changes our society might make in order to improve the state of end-of-life care. Record their responses. Possible responses might include:

- Improve training of medical professionals in end-of-life care;

- Implement public policy that supports the end-of-life care preferences of our citizenry;

- Inform the public of its options for end-of-life care and the steps to take to ensure preferences are understood and honored.

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

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

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

The Importance of Talking About End-of-Life Care and Making Plans

Discuss how important it is to talk with your loved ones about end-of-life plans. Stress that the peace of mind that comes from being able to honor a loved-one's wishes is invaluable, and remind participants that even though it may be difficult to talk about death, the actual process of having conversations may be reassuring. Mention that the end of life does not have to be a wretched event. To the contrary, it can be a time of richness, growth and peace.

Get participants to list some of the steps they might take to be prepared for the end of life and record their responses. Possible steps include:

- Clarify your own values related to end-of-life issues.
- Learn about your options for end-of-life care.
- Have conversations with your loved ones about your values and preferences for end-of-life care.
- 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, durable power of attorney for health care decisions, and do not resuscitate order. Mention that you will be reviewing advance directives in the next section of the program.
- Engage in financial planning. Mention that Extension offers a five-part Estate Planning Series to help people learn about wills, trusts, letter of last instructions and other estate-planning issues. As an optional step, provide these documents for participants.

Advance Directives

Describe what advance directives are and explain how they are used. Pass out a copy of a Living Will and Durable Power of Attorney for health care decisions so participants can see what they look like. As an optional activity, hand out copies of advance directives to participants, along with copies of the instructions on how to complete them, for participants to take home. You may want to do this at the end in order to keep participants' attention focused on the program. If you do not plan to hand out copies of advance directives, make sure to tell participants how they can obtain them (e.g., from physicians, hospitals, county health departments, or the Internet). Laws surrounding advance directives vary from state to state. If they anticipate moving, or if they want to obtain a form for someone living in another state, the following web site offers state-specific advance directives: www.partnershipforcaring.org.

References

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Webb, M. (1997). *The Good Death: The New American Search to Reshape the End of Life.* New York: Bantam Books.

Role Playing

Mention that it is difficult for many people to talk about death and dying with their loved ones. Have participants break into pairs in order to role play having conversations on this topic. Have them start with the questions that are listed below and on Page 3 of the fact sheet, but let them insert questions of their own if they wish. To keep the role play to a manageable length of time, you may want to select two or three questions for participants to ask each other. Mention that these questions come from a workbook called *Caring Conversations,* that is available from Midwest Bioethics Center in Kansas City (1-800-344-3829; www.midbio.org). Questions 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?

What is Palliative Care?

Describe the medical specialty, palliative (comfort) care. Share that the goal of palliative care is for a dying person to have the best quality of life possible. Palliative care not only looks after a person's medical needs by providing good pain management and other "comfort care" treatments, but also considers the emotional, social and spiritual needs of the patient. Note that, according to palliative care expert, Dr. Ira Byock, "...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."

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 caregiver 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 caregiving 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 caregiving, contact:

National Caregivers Association
1-800-896-3650 or

www.nfcacares.org

One Option: Hospice Care

Describe hospice care as an example of palliative care that focuses on enhancing the quality of a person's remaining days. Describe the services that hospice care typically includes (e.g., visits from specially-trained registered nurses, nurse aides, social workers, chaplains, bereavement counselors, and volunteers). Point out that while hospice medical care focuses on providing pain relief and managing other symptoms so that a person is comfortable, it also addresses the emotional and spiritual needs of the dying person and family members (both the dying person and his/her family are considered the unit of care). Note that hospice care is available to anyone with a terminal illness, not simply cancer patients. It can be provided in many different settings, including private homes, nursing homes, and hospitals.

Note that nobody should feel pressured to accept Hospice care and that patients are free to change their minds even after Hospice care has started. Point out that hospice services are covered by Medicare when a person is expected to live for six months or less. Make sure to emphasize that families often select Hospice care too late for it to be of much help (the median length of care of Hospice patients is only 25 days) and note that 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. Point out that the Association of Kansas Hospices (AKH) can help people find a Hospice program locally or anywhere in the United States. Contact information for the AKH is listed in the fact sheet.

A Caregiver's Story

A Caregiver's Story. Give participants a few minutes to read "A Caregiver's Story" (at right and on Page 6 of the fact sheet). Some possible discussion questions are:

- Would you be willing to serve as a home caregiver for a loved one who was dying, as Betsy did? Why?
- Despite the "nitty-gritty yuckiness" of care giving, Betsy said that this was "treasured time" with her mother. Why do you think that was so?
- Why do you think it was so important to Fan to have chats with the Hospice aides about events in their lives?
- Why do you suppose that home care giving sometimes puts a strain on marriages or other family relationships?
- What are some services or policies that our society might offer to assist home care givers and lessen the sacrifices that care givers, such as Betsy and Chuck, often make?

ON OUR OWN TERMS Moyers on Dying

In September, 2000, Public Television aired a four part series on end-of-life issues entitled, *On Your Own Terms: Moyer on Dying.* In this series, journalist Bill Moyers reports on the end-of-life journeys of more than a dozen individuals, their families and their caregivers as they grapple with the challenging events, decisions and opportunities that arise at the end of life. In addition, this series presents the views of medical, legal and public policy experts regarding cultural attitudes toward death and ways to improve end-of-life care. You may wish to play segments of this series for your audience to illustrate concepts being discussed in this lesson. Sometimes it is easier for people to discuss end-of-life care when they are talking about other people's experiences.

To find out how you can obtain a leader guide to accompany this series, contact the LIFE Project at 1-888-202-LIFE.

Pain Control

Point out that a big fear of many people is a lingering, painful death. Note that, due 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. Emphasize that families must often serve as advocates for their loved ones, not only in helping them obtain pain relief but in every step of end-of-life care.

The Question of Tube Feeding

Discuss the topic of providing artificial nutrition and hydration to dying persons. Note that this is a very personal decision that may be helped by discussions with health-care providers, social workers and clergy members. Have participants consider the following points:

- There is no evidence that tube feedings and intravenous fluids make death less painful.
- 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).
- 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 allows a disease to follow its natural progression.

Share the idea that 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, Dr. Ira Byock, suggests that there are five messages that may help persons who are dying and their loved ones to feel at peace. Ask participants what they think of the following five messages:

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

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