## *ABOUT THIS MODULE*

Included here you will find a sampling of some of the pages out of this educational module which is intended for use by nursing homes who wish to promote more social, non-traditional models of long-term care. The intent of these modules is to assist organizations in implementing progressive, innovative approaches to care that should make a significant difference in the quality of care and the quality of life for those living and working in long-term care environments. Full copies of the modules in pdf format are available. Please contact us for the fee schedule for these modules at gerontology@ksu.edu.

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Center on Aging
Kansas State University
103 Leasure Hall
Manhattan, KS 66506-3501
785-532-5945
gerontology@ksu.edu

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The development of PEAK materials was supported by the Kansas Department on Aging and the Kansas Department of Social and Rehabilitation Services through a Title XIX contract and matching funds provided by Kansas State University, Kansas Association of Homes and Services for the Aging, Kansas Health Care Association, and volunteers from the Long-Term Care profession.

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Revised December 1, 2003

# Pioneering Change

## End-of-Life Care Education Module

to

**P**romote **E**xcellent **A**lternatives in **K**ansas

**Nursing Homes**

# Table of Contents
# End-of-Life Care


**Course Objectives** . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .2
**Pretest** . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .3
**Note from Dr. Gayle Doll, Director of the K-State Center on Aging** . . . . . . . . . . . . . . .5
**End-of-Life Care** . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .6
Introduction . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .6
Envisioning an Ideal Death Activity . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .7
**Traditional Model** . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .8
What is Palliative Care? . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .8
What is Hospice Care?. . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .8
**Basic Elements of Excellent End-of-Life Care** . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .9
Palliative Care Respects the Goals, Likes, and Choices of the Dying Person . . . . . .9
End-of-Life Care for Residents with Dementia or Alzheimer's Disease . . . .11
Palliative Care Looks After the Medical, Emotional, Social, and Spiritual Needs of the Dying Person . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .12
Medical Needs . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .12
Emotional Needs. . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .12
The Review of My Life Activity . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .13
Social Needs . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .17
Spiritual Needs . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .18
Palliative Care Supports the Needs of the Family Members . . . . . . . . . . . . . . . . . .20
Bereavement . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .21
Palliative Care Provides Access to Needed Health Care Providers . . . . . . . . . . . . . .22
Palliative Care Provides Excellent Care at the End of Life . . . . . . . . . . . . . . . . . . . 22
The Death Rituals Activity . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . 23
**Holistic Model** . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . 23
**Conclusion** . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . 27
**Projects** . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . .29
**Post-test** . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . 32
**Pretest and Post-test Answers** . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . 34
**Resources for Palliative Training** . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . 35
**Resources for Pain Management** . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . 35
**References** . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . 36
**Clip Art Credits** . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . . 40

## Course Objectives:

1. Increase awareness about commonality of death in nursing homes.

2. Understand the principles of palliative/hospice care.

3. Embrace a holistic approach to end-of-life care.

4. Increase knowledge about nursing homes' practices and rituals enhancing end-of-life care.

*Note from Dr. Gayle Doll, Director of the Center on Aging at Kansas State University and co-primary investigator for the PEAK-Ed initiative:*

I started my training in gerontology in kinesiology because I wanted to work with older adults in maintaining high levels of functional ability as long as possible. I wanted to "cheat" the nursing homes because, like so many others, I found these institutions to be highly aversive. Like many others I would have chosen death over living in one.

Once I started to examine this attitude I felt it was important to do what I could to improve the culture of institutionalized care for the elderly. Culture change made intuitive sense for me, but it was an article by V. Engle (1998) that really put a voice to my vision of what these changes should be.

When persons who have lost loved ones under hospice care are asked to evaluate that care, they express high levels of satisfaction. Satisfaction with end-of-life care in nursing homes is much lower. What constitutes the difference? I believe several things:
1. Hospice treats the family as well as the patient.
2. A great deal of attention is paid to alleviating pain and fear.
3. Death is confronted rather than denied so that important developmental processes can be addressed.

I believe that the last point is very significant, maybe not just in nursing home cultures but in American culture as a whole. How many times have you heard nursing home personnel say adamantly "Our home is not a place to die—it's a place to live!"?

Why not make our homes THE places to die—places where important developmental issues can be addressed, so residents and their families can be ready for an inevitable life event. Engle calls this part of life the "living-dying" interval.

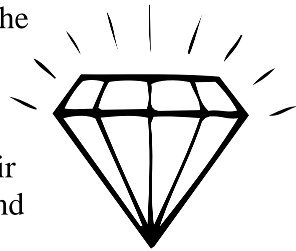
One of the critical elements of hospice care is a diagnosis of less than six months to live. Would it be appropriate to put this determination on every new resident who enters a nursing home? Of course not. Many residents will rehabilitate back to another setting but the average age of the institutionalized elderly is 85. At age 85, many, if not most, persons are beginning to think about death. These thoughts should and could be openly discussed.

It is our hope that this module will promote discussion about these issues within your home. This module is a little different from past modules in that we present some ideas that have not been tested by research, and we do not have a lot of examples from here in Kansas. If you have found ways to improve care that leads to greater acceptance of death and the "living-dying" interval, we invite you to share them with us, and we will post them on our website.

Gayle Doll

# End-of-Life Care

> "Elders are the jewels of humanity that have been mined from the earth, cut in the rough, then buffed and polished by the stonecutter's art into precious gems that we recognize for their enduring value and beauty."
>
> -Unknown



## Introduction

At the beginning of the 20th century, most people died in their own homes. Today, approximately 500,000 persons die in U.S. nursing homes every year. This is nearly 20% to 25% of all deaths. Among people aged 85 or older, 43 % of deaths occur in nursing homes. It is estimated that by 2020 nearly 1 in 2 persons will die in a nursing facility. Nursing homes will become the primary place for dying in this country (Teno, 2003). Thirty percent of patients who die in hospitals have been transferred there from nursing homes just a few days earlier (Johnson, 2005). Certainly, death is no stranger in the long-term care setting.

However, the present culture is in denial of death. Death is a forbidden topic. When the subject of death is discussed, euphemisms such as "passed away," "expired," or "left this world" are used. Perhaps, it is time to recognize the reality that a majority of deaths occur in nursing homes and that the quality of this experience of dying is typically far from excellent. To improve care for older people at the end of life, all aspects associated with death need to be openly discussed, education needs to be available, dying and death need to be accepted as part of life, and viewing death as a natural progression of life should be promoted (Crow & Werth, 2005).

Caring for people at the end of their lives can be very difficult. However, knowledge about the process of dying significantly alleviates this problem and brings many benefits not only to a dying resident and their family members but also to staff members caring for a resident. Each person is entitled to die in comfort, as free as possible from physical, emotional, and spiritual distress. Dignity and the value of human life drive the provision of high quality end-of-life care to people who are at their most vulnerable stage of life. Palliative or hospice care and their principles are essential for achieving this goal. (Gross, 2003).

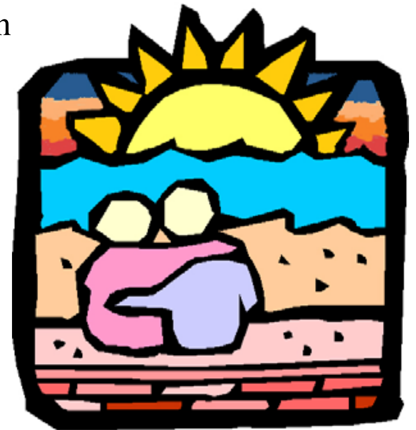
> ***DID YOU KNOW?***
>
> - Over 23,720 Kansans died in 2004 (Kansas Annual Summary of Vital Statistics 2004)
> - About 80% of them do not die suddenly (Kansas Annual Summary of Vital Statistics 1997)
> - About 46.2% died in a hospital
> - About 20.5% died at home
> - **About 30% died in long-term care facilities**
> - About 3.3% died elsewhere (Brown University Center for Gerontology 2001)

# Traditional Model

## What is Palliative Care?

"Palliative" is synonymous with "soothing," "comforting," and "calming." Palliative care is defined as whole-person care for persons whose diseases are not responsive to curative treatment. Persons with a life-limiting disease may receive palliative care early in the course of their illness to relieve pain and other physical symptoms and to assist them in coping with how the illness impacts their daily living and family.

The most effective palliative care occurs when it is integrated in the daily care of a nursing home's culture (Jerrard, 2004). The World Health Organization (2002) adds that "palliative care is an approach which improves quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual." With palliative care all the services and treatment of the disease are offered by providing the physical, spiritual, social, and emotional aspects of caring.



## What is Hospice Care?

A dictionary lists words like "home rest" and "sanatorium" as synonyms for hospice. "Hospice" is the term for a special program of palliative care for terminally ill (dying) patients and their families. The goals of both palliative care and hospice care are to relieve suffering and to improve quality of life at its end. The focus of both philosophies of caring for a dying person is identical. The key difference between the two is that hospice care is defined within the context of Medicare benefits. Medicare and Medicaid do not recognize palliative care as separate care (Jerrard, 2004). A hospice referral requires a prognosis issued by a physiciaon that death is expected within six months or less.

> *"You matter because you are you. You matter to the last moment of your life and we will do all we can to help you die peacefully, but also to live until you die".*
>
> *Dame Cicely Saunders, founder of the modern hospice movement*

## Basic Elements of Excellent End-of-Life Care

Palliative care is a process incorporating many disciplines. It requires a strong management overlooking an intensive training process and its consistent and careful implementation by all staff members. The promotion of excellent end-of-life care needs to begin with a deep understanding of the philosophy of palliative care.

The five principles of palliative care are:

1. Respecting the goals, likes, and choices of the dying person;
2. Providing for the medical, emotional, social, and spiritual needs of the dying person;
3. Supporting the needs of the family members;
4. Providing access to needed health care providers;
5. Providing excellent care at the end of life (Kansas Life Project).

## Conclusion

Studies demonstrate that a culture of positive aging/excellent end-of-life care does not just evolve but must be actively created by health care providers, residents, family members, educators and other stake holders. Hopefully, this module will inspire nursing home caregivers to promote and implement a culture of positive aging and excellent end of life in their facilities.

For many nursing homes, practicing palliative principles with all residents immediately upon their admission does not seem feasible. Traditionally, hospice services have been provided in nursing homes by independent for-profit or not-for-profit companies under contract. Consequently, palliative care principles are not familiar to all staff. Kansas Masonic Home in Wichita has become the first long-term care facility in Medicare's 20-state central U.S. hospice region to be certified for hospice services using its own internal staff (KAHSA, 2006). This model cannot be replicated by each nursing home in Kansas due to many obstacles like facility size, lack of resources, etc. However, the understanding of palliative philosophy should help in the implementation of its principles for each resident during his/her entire stay at a nursing community.

All the described activities can be easily replicated in each home. These activities strengthen relationships between care givers and recipients and add a spiritual dimension to moments spent together. It is all about meaningful relationships, respect, and time allocated to cultivate these relationships. "Successful aging…can best be achieved in relationships" (Vailliant, 2002, p.308).

Using palliative care principles is more feasible in resident-centered homes where each resident is seen as an individual with his/her own preferences, wishes, values, and lifestyle. In these homes "distant relationships" between residents and staff are nonexistent. On the contrary, the core of the quality of life in these homes for both residents and staff is based on their mutual relationship and its growth.

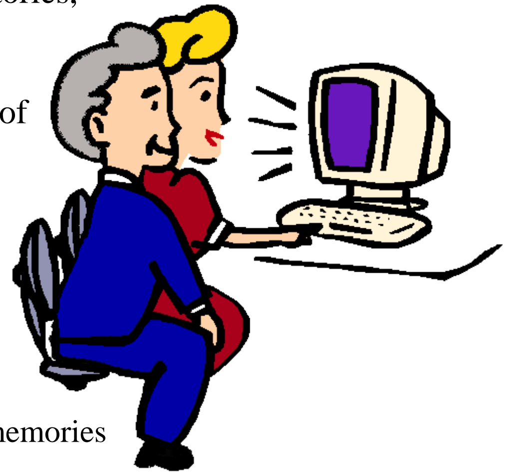
"*We need to begin now to create the type of environment we would like to live* (and to die -Center on Aging) *when our time comes. Just as it takes a village to raise a child, so it takes a village to care for the elderly.*"

(Baker, 2002)

**3. <u>The Review Life Project</u>:**

Prior to this activity, develop a list of questions that will help a resident talk about his or her life and help you both stay on the task. You may want to involve a resident's family members and friends in this project. Some residents will be comfortable telling a life story to a few staff members. In this case, the project has to be well managed by these staff members. Review what has been written prior to resuming collection of new memories. Staff should establish a regular meeting time with a resident to emphasize the importance of the task.

Turn on the computer or open a notebook, and ask a resident how to title his memories ("My Life", "John's Story" etc.). Write down a resident's stories, recollections, and thoughts. You can add photos, small mementos, and favorite recipes. Ask a resident what these particular photos mean, maybe there is a story behind a few of them. What trips did they take, who are the people in the pictures, what are the names of their pets? What places did they live? What kind of jobs did they have? When was a particular meal served? Who taught them this recipe? Was it well liked? Meet with residents as often as they want to share their stories and as often as your schedule allows you to spend extra time with residents. Involve volunteers from your community to record residents' memories. Some of these memories may shed new light on your community history.



*Assessment and evaluation:* Ask residents why recording their lives is meaningful. What are their life lessons they want to share with younger people? What would they do different today if they could change the past? What are their most proud and cherished accomplishments? To whom do they want their life reviews to be sent?