# Pioneering Change

## End-of-Life Care Education Module

to

**Promote Excellent Alternatives in Kansas Nursing Homes**

# *ABOUT THIS MODULE*

This educational module is intended for use by nursing homes who wish to promote more social, non-traditional models of long-term care. The intent of this module 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.

Information provided on specific nursing homes was obtained through interviews with staff members and the print version of this information was approved by same prior to publishing.  Information was accurate at the time of publication.  There are no guarantees that the nursing home or program will be exactly as described at any time later than the date of publication of this document.  Mention of particular services, methods of operation or products does not constitute an endorsement, but are to be used for informational purposes only.  Opinions expressed by individuals in this document do not necessarily represent the opinion of the KSU Center on Aging, the Kansas Department on Aging, or the Kansas Department of Social & Rehabilitation Services.

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# 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.

# Pretest

*The pre-and post-tests included with this module are optional. The questions provide information about the material to be covered and can be used for learning self-evaluation.*

1. Which of the following statements are true for palliative/hospice care principles?
    A. Goals, likes, and choices of the dying person are followed.
    B. Medical, emotional, social, and spiritual needs of the dying person are met.
    C. Needs of the dying person's family are met.
    D. The dying patient has access to needed health care providers.
    E. Excellent care is provided to the dying person.
    F. All of the above.

2. What percent of deaths occur in nursing homes in the U.S.?
    A. 5-7%
    B. 10-12%
    C. 38-42%
    D. 20-25%

3. What is median length of hospice care for a dying person?
    A. Sixty days
    B. Three and a half months
    C. Six months
    D. Twenty-five days

4. An advance directive is:
    A. A legal document identifying division of inheritance.
    B. A description of what treatments are acceptable to a person when he/she is not able to make a decision due to an advanced disease.
    C. One of the documents required upon admission to a nursing facility.
    D. None of the above.

5. What are the benefits of spiritual care offered to a dying person?
    A. Helps him or her find meaning at the end of life
    B. Helps him or her accept death
    C. Helps him or her grow as a person
    D. All of the above

6. Which definition of Elder is false?
    A. An older member of a Native American tribe
    B. An older community member to whom people come for advice
    C. The oldest person in a group
    D. A school child

7. The last stage of a person's life is usually characterized by:
    A. A desire to pass one's life experience to a younger generation.
    B. A review of one's life.
    C. Preparation for one's death.
    D. Despair if a person has not accomplished his/her life goals.
    E. All of the above.

8. Which of these statements are true?
    A. Depression is a normal part of the dying process.
    B. Most people prefer to die alone.
    C. When a loved one is dying in a nursing facility the family receives the majority
       of its support from frontline workers.
    D. Most people are not comfortable talking about death.
    E. Both C and D

9. Which of the following describes a Regenerative Community?
    A. An emphasis on energy recycling
    B. An emphasis on the importance of community
    C. All community members contribute work for the good of all
    D. An emphasis on physical fitness

10. What are possible reasons for residents to talk about their past?
    A. A resident's short-term memory span is poor.
    B. A resident likes to reminisce about his or her past.
    C. A resident tries to identify the meaning of his or her life.
    D. A resident is very critical of the present time.
    E. All of the above.

Answers can be found on page 34.

*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
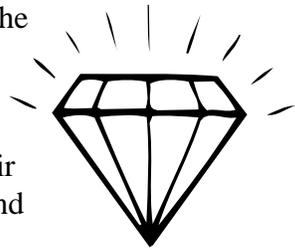
## Introduction

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).

## Envisioning an Ideal Death Activity

Henderson (2003) developed the following tool to help staff not only envision a good death but also be more comfortable with the subject of death. The activity should be conducted, if possible, in a small, softly lit, and quiet room, preferably with just a few people but can be conducted in a large group. Soft instrumental music via CD can provide a nice background. Read the instructions and questions slowly to staff and give them enough time to think.

Close your eyes. Relax. Take slow deep breaths.

-Recall memories of a good death that you have seen. It could be that of a family member or resident you have cared for. Or, think of someone whom you would like to see have a good death. What made it good?

-Imagine that this person is dying here, in this nursing home. Picture this person's face and expression. What would you like to provide to make sure that this person has a good death?

-Imagine that this person is in one of the rooms in your nursing home. What in this room bothers you? What would you do differently to create a pleasant environment for your loved one/resident?

-Do you hear any sound or music there? What sounds, music, or voices would you choose for your loved one/resident, according to their preferences?

-Is there enough light or too much? Do you want the windows opened or covered with curtains? Should there be more blankets on the bed?

-Who is in this room? Who do you think your loved one/resident would like to be in this room? What activities would you like to have?

-How do you know what your loved one/resident wants? What would they ask for? What would you do if your loved one/resident cannot communicate?

-What kind of interaction do you expect from staff to help you during this difficult time?

-What would help you deal with the

death of your loved one?

-What rituals offered by the nursing home would help you grieve? What kind of relationship would you like to have with the nursing home a few months after the death?

Following the session, ask participants to share their thoughts and insights.

List of questions developed by Henderson, M.L., Hanson, L.C., & Reynolds, S.K. (2003). *Improving nursing home care of the dying: a training manual for nursing home staff.* The list modified by the K-State Center on Aging, with the author's permission.

# 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).

## Palliative Care Respects the Goals, Likes, and Choices of the Dying Person

Nobody can predict how one is going to function at the end of life. Some people lose their ability to express their wishes, and their end of life is decided by family members, a physician and/or nursing home staff. To ensure that residents maintain the power to decide for themselves until the end of life, nursing home staff should encourage residents to develop an advance directive care plan upon admission to a facility.

In order to effectively facilitate this process, a resident should have the opportunity to discuss the plan with family members, a spiritual leader, and nursing home staff prior to transferring the wishes to a written document. To help a resident with this discussion staff can present him/her a list of questions that will guide the process more smoothly. Residents should be familiarized with the philosophy of hospice service, and his/her wishes should be reflected in the care plan. Once a resident is diagnosed with a terminal illness, its nature and anticipated course should be discussed to provide understanding of the illness. This is a good time to review available treatments.

An advance directive is the only way to be sure a resident's wishes will be followed when he/she can no longer

express them or lacks the mental capacity to act for him/herself. It is a broad term that applies to living wills and medical powers of attorney. The directive describes what kinds of treatment a dying person does not want to have and what kinds of care he/she wishes to receive. Advance directives take many forms as laws are different in each state. Kansas nursing homes need to use an advance directive as defined by the state of Kansas. This resource is accessible on-line at www.caringinfo.org/files /public/kansas.pdf. In Kansas about 53% of nursing home residents have a formal advance care directive (Kirk, 2006).

To some residents, selecting a certain medical treatment may be associated with religious or personal value norms that govern what medical procedure is acceptable or not (Kansas Life Project). One cannot overestimate the need to have nursing home staff talk to residents and their family members about residents' cultural and spiritual preferences and the rituals associated with their culture and religion (Gazella, 2006). Studies have shown that racial, ethnic, social, economic, educational, and gender groups have significantly different preferences not only during life, but also in their end-of-life health care wishes (Kumar, 2006).

## Case Study: Cultural Effects

*Wei-ge, an 89-year old Chinese female, had been in the Forest Valley Home for a few months. At the time of her admission, she was very frail, and all of her ADLs were conducted with the help of CNAs. Wei-ge's appetite was very poor, and she hardly touched most of her food. The doctor examined her and diagnosed that she was close to her death. Wei-ge's family was notified about her health status.*

*To the staff's horror, they discovered that the family was forcing food into Wei-ge. The administrator and DON asked the family to come to the office to discuss this inappropriate and dangerous behavior. The family members did not understand the administrators' reactions and were appalled that their mother might be condemned and not have peace in her afterlife journey. After some discussion, it was identified that the Chinese believe that a dying person cannot leave the earth with an empty stomach.*

*After further discussion, the family and the Forest Valley Home administrators reached a compromise that was satisfactory for both sides. Wei-ge's daughter was allowed to moisten her mother's lips with green tea. Both parties were able to develop a plan that acknowledged Chinese culture and followed the nursing home's regulations at the same time.*

What should a nursing home do in case a resident's beliefs/values are drastically different from a home's policy?

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How should a nursing home find out about the specific needs and beliefs of each resident?

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Have you ever faced a situation where meeting a resident's needs or wishes would have meant breaking the home's rules or regulations?  How have you handled it?

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**End-of-Life Care for Residents with Dementia or Alzheimer's Disease**

About 1.5% of people 65 and older have dementia, and this number doubles for every four year increase in age.  At the age of 80 and above, 30% of people have developed dementia.  It is estimated that 14.2% of nursing home residents have Alzheimer's disease.  Palliative care for residents with dementia focuses on prevention of falls, choking, and pressure ulcers (Sattinger, 2005).  Palliative

service is vital for providing care not only to a dying person whose communication is impaired but also to his/her family (Forbes-Thompson, Bern-Klug, and Gessert, 2000).  Most people do not realize that dementia is a terminal illness and assume that people with dementia die from causes like a heart attack (Forbes-Thompson, Bern-Klug, and Gessert, 2000).  In 1997, about 42% of nursing home residents were diagnosed with dementia (Pandya, 2001).  Johnson (2005) quoted studies that indicated that 1.1% of residents with advanced dementia were identified by clinicians as having a life expectancy of less than six months.  However, seventy-one percent of the patients in the study actually died within a six month period.

- Lakeview Village in Lenexa, Kansas holds "Caring Conversations" with family members in order to find out about their loved one's preferences when residents cannot speak for themselves.  The entire staff is trained to be able to detect if residents and their families are ready to discuss issues surrounding death.  They offer a special book to residents and families to facilitate conversation about decisions regarding care during the dying stage.  Their palliative team includes the administrator, the head of the social work department, a nurse practitioner, and a full-time chaplain.  After each death, the team discusses its actions in order to further improve palliative care in their home.

## Palliative Care Looks After the Medical, Emotional, Social, and Spiritual Needs of the Dying Person

### Medical Needs

*Depression*
It is estimated that at least 25% of end-stage patients are diagnosed with depression or display depressive symptoms but do not receive medication. Staff may view depression as a normal event associated with this stage. It is imperative to remember that depression is a treatable and often reversible disease (Simon & Littlehale, 2005). There is no reason for a person facing death to deal with untreated depression at the end of life. The final months and even days of life are still open doors for personal growth, such as self-reflection and working on interpersonal issues, and finding joy through sharing final moments with loved ones (Crow & Werth, 2005).

*Pain management*
A guiding principle of excellent end-of-life care is to provide relief and prevention of suffering to allow the least painful death possible. Nursing home residents' quality of life is significantly improved when they receive hospice care due to the superior pain assessment and decreased number of invasive procedures (Berger, 2001). Palliative care not only addresses physical pain, but also psychological, social and spiritual problems that might cause people to suffer if their specific needs are not met. The selection of medical treatments is associated with very personal values that are a reflection of a person's psychological, social and spiritual principles. Staff should remember that some residents suffering from terminal illness may not want heroic measures to prolong their lives or decrease their physical pain. Several organizations that provide information about pain management are listed in the back of the module.

### Emotional Needs

Life review is a way to start the process of looking back on one's life and help a dying resident reflect on his/her life value, experiences, accomplishments, and people who are important to him/her, both deceased and alive. The purpose of reflecting on one's life is to bring closure to one's life and, consequently, help a dying person accept the last stage of his or her life. Through these conversations a person may achieve surprising personal growth, even in the last few moments of life.

Storytelling serves several functions:
- It gives residents a tool for organizing and shaping personal experience and thought; and
- It allows residents to form connectedness and intimacy with the person with whom they share stories; and

- It often helps people feel that they contribute to something bigger than themselves, and this enhances their understanding of the relationship between spirituality and healing (Skokan & Bader, 2000).

Cohen (2003) notes that "autobiography for older adults is like chocolate for the brain."
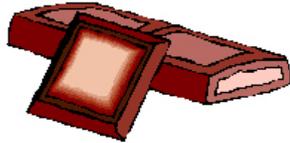
End-of-life conversations can be a pathway leading a dying person to a better way of dying. *Embracing Elderhood*, created by the Eden Alternative's Eden at Home program, involves community members who come to facilities, listen to elders' life stories and record them. Legacies, residents' life stories, are part life stories and part "gift". Residents gift a younger generation not only with their stories but also with wisdom and life experience. Helping residents write "legacies" can help build relationships between caregivers and elders in a very meaningful way. Fairport Baptist Homes in New York utilize technology for recording residents' life stories (Lourde & Sanders, 2006). Using a computer with a software program may attract younger volunteers and increase their involvement with recording elders' life stories.

- St. Francis Good Samaritan Village in St. Francis, Kansas tells a resident's life story through slides. Each month a new resident is chosen to review his

or her life. Old and new pictures meaningful to the resident are put on slides. The slides accompany each story and may also help evoke old memories. With a resident's permission, his or her life is told to other residents. The slide-story is sent to a resident's family after the resident dies. There is a waiting list for this very popular activity.

## The Review of My Life Activity

Imagine that you want to tell your children or younger friends your life story.

How would you title it?

What is significant about you that should be included in your life story?

What are your interests and hobbies?

What places have you lived throughout your life?

Who are the important people in your life?

Can you identify 2-3 happy moments and 2-3 miserable events in your life?

What have you learned from your failures?

How have you coped with disappointments?

What are your dreams?

What dreams have you met?

If you were asked to pass one life wisdom or experience to a younger generation what would it be?

"If you don't know the trees you may be lost in the forest, but if you don't know the stories you may be lost in life."
- Siberian Elder
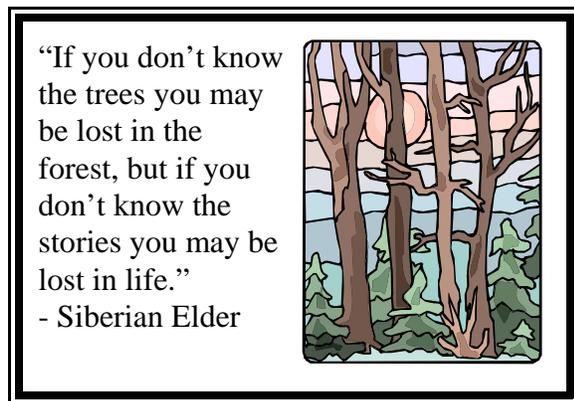
Music can be a wonderful facilitator for expressing one's feelings. Music can unblock painful emotions such as fear, anxiety, sadness, and anger that disturb the process of accepting one's death. Music touches deep emotions in people and may help a dying resident share his/her emotions. It may aid them to acknowledge their emotions, help resolve old issues and enable reflections about life reaching its end.
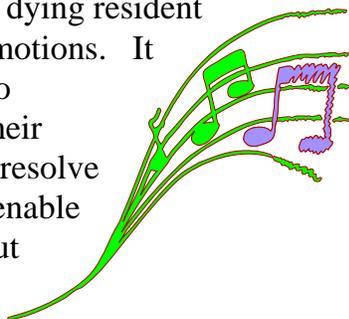
Music is used more and more often at the bedside of dying people. A person who is dying may not be able to communicate or may communicate only in a limited way. A dying person may be comatose or in a state of altered consciousness, and his/her response to music may be hard to identify. The goal of music is to help a dying person "die the good death." It is widely recognized that music brings many benefits to a dying person and their family members; it also aids family members in their grieving and healing process.

In response to this need some programs, like *Chalice of Repose Project*, train musicians to provide music to dying people in a variety of places, including nursing facilities (Cassidy, 2004). Historically, music played on a harp is used most often for its calm sound and ability to help with emotions like anxiety, fear, and pain (Gross, 2004). There are many music CDs and tapes that can be a substituted for live music. If possible, a person should be asked for music preferences. A former choir member may find great comfort in hearing the work the choral group rehearsed decades ago.

## Case Study:
*Lillian was very quiet and minimally engaged in her new nursing home. Staff kept encouraging her to leave her room and join other residents, but Lillian often chose to stay in her room.*

*One day, a musician was invited to sing his songs to the residents. He started the program by singing several songs that were popular in the elders' youth. Many of the songs evoked memories for the participants and created a festive mood among them. Then the musician started singing songs he wrote himself. The lyrics were about his life, dreams met and not met, a lost love, faraway friends, children who left their hometowns, and places he wanted to see but never did. The musician was playing on a guitar. The melodies with the lyrics touched many people's emotions.*

*This was the first time that Lillian stayed the entire activity time. The artist was coming back each month, and Lillian never protested about leaving her room when invited to his concert. After each concert, she shared a few stories from her own life with her favorite staff. Music helped Lillian review her life and pass decades of her wisdom to a younger generation.*

What has helped Lillian be more engaged in the nursing home?

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What clues does Lillian's reaction to music provide about her needs and desires?

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How can staff help Lillian be more active even when the musician is not there?

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## Case Study:

*Harry was labeled by staff as a difficult resident. He was very critical of everything staff was doing. He never thanked them for anything they did. Harry's sarcasm and constant criticism discouraged staff from having any interaction with him unless it was absolutely necessary. Minimal interaction was encouraged by Harry himself who kept demanding staff leave his room right after they helped him with his ADLs.*

*A local high school developed a history project that was proposed to the nursing home. Students asked to be allowed to talk to the World War II Veterans. The nursing home administrator asked appropriate residents to*

*participate in the project. She was very reluctant to ask Harry to take part in the school assignment. To her surprise Harry was interested in the project. He was assigned to a junior whose knowledge about the war was quite extensive.*

*At first, Harry only answered the student's questions, but after a few sessions, he provided more and more memories on his own. Often Harry got upset when he could not remember the facts right away. However, the presence of the young student and the student's knowledge about the war somewhat decreased Harry's anxiety. Staff noticed that on a day the student was scheduled to see him, Harry was seen walking up and down the hall. Harry started reminiscing with staff after the student was gone. He was telling staff about particular stories he shared with the student that day. Staff learned that when Harry got home after the war was over his young wife was involved with another man. Harry did not remarry until he was retired. His wife died right after Harry had a stroke. Harry spent a few weeks in a rehabilitative center and then was placed in the nursing home.*

*After the school project was complete, staff was afraid that Harry would again manifest his anger and dissatisfaction. However, since they understood Harry's source of anger they could relate to him better. The time Harry spent working on the project helped him connect to a few staff members. They noticed that he was friendlier to them and less critical of their performance. The staff encouraged*

*Harry to talk about his past, and this deepened his relationship with a few of them. Harry was not labeled as a difficult resident anymore since the number of his outbursts had significantly decreased.*

What were Harry's main reasons to feel angry and disappointed?

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Why do you think he agreed to participate in the school project?

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What helped Harry deal with his anger?

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How would you help residents, like Harry, identify the source of their anger?
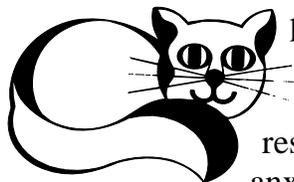
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Staff at Bon Secours in Florida introduced *Angels Passing By* that offers dying residents lotions, oral care items, scented pillow spray, aromatherapy, shampoo and soap that can be warmed up in a microwave. The residents' dietary wishes are granted, and "spa days" and trips to favorite places are available. Staff members try to help a resident keep meaningful routines and habits, like assisting a female resident with maintaining her daily make-up (Gold, 2003). Each simple pleasure that can be honored becomes a very special gift to a person whose life is ending.

**Social Needs**

Equally important to palliative care is social time offered by family members, staff, other residents, and volunteers. Calvary Hospital in Bronx, New York City created the *Connection Program* for residents who have no family or whose family lives at a distance. A nonmedical staff member adopts a dying person and spends time with that person. The hospital also uses trained volunteers who are very valuable in providing additional support to a dying person (Sattinger, 2006). Some facilities also utilize animals whose presence has a calming effect and decreases dying residents' pain and anxiety (Gold, 2003).

Studies indicate the importance people place on human contact and prayer at the end of life. A Gallup national survey in 1997 asked people about the kind of human interaction they would like to have if they were dying. Fifty-five percent would like to have someone to share their thoughts and fear, 54% just want someone to be with them, and 47% want someone to hold their hands or touch them. Fifty percent would like to pray alone. Fifty percent would like someone to pray for them (Lynn, Schuster, and Kabceneu, 2000).

- A few of the Medicalodge residents in Kansas City are comatose. The activity staff felt uncomfortable that they were not able to offer these residents activities that could connect them to the community. After some discussion, the activity staff started providing the residents with a regular massage using a scented lotion gently rubbed into their skin and talked to them during the massage sessions. This is a meaningful way to maintain a relationship with residents who cannot communicate anymore. Massage provides the residents a regular physical touch that is essential for their physical comfort and connection with people. This form of contact with non-communicative residents helps staff continue relationships with these residents. A gentle massage, when appropriate, may provide comfort and a feeling of safety to a dying person.

- The staff at Medicalodge in Wichita provides aromatherapy to its residents with Alzheimer's to stimulate their senses.  This serves as another method of communication with these residents.

**Spiritual Needs**

The end of life can either be a depressing, painful, and isolating experience or a time of great love and beauty. When a person experiences spiritual transcendence, the individual's experience of death is transformed, and a spiritual healing can take place.  Spirituality may be enhanced by the sadness of a terminal illness and can heighten the meaning of life.  One's life is put in perspective.  Death leads people to the realization of deeper truth and the need to strengthen or find the connections, relationships, and meaning that can give commitment and hope.

> Spiritual needs are encompassed by the following:
> ▸ The need for meaning and purpose in life
> ▸ The need to give love
> ▸ The need to receive love
> ▸ The need for hope
>
> (Pilgrims Hospice Society, 2006)

The role of caregivers is to offer the opportunity for residents to meet these needs.  Spiritual support and counseling are essential components of excellent care for a dying resident.  Clergy and other spiritual counselors need to be available to visit residents to provide spiritual support.  Spiritual care is a personal process.  It may include helping a dying resident and his or her family explore what death means to a resident facing the end of life, resolving "unfinished business," saying goodbye to loved ones, and performing a specific religious ceremony or ritual.

The fear of death can be caused by a fear of pain or abandonment.  Hospice professional staff are well trained to offer bereavement and spiritual assistance that can help residents and families begin the process of accepting death.  They assist individuals in finishing important tasks, saying their final goodbyes, healing broken family relationships, distributing precious belongings, and completing a spiritual journey (Naierman, 2004).  A modern cancer treatment that embraces the emphasis on the patient's mind and spirit attempts to connect the healing process to activities, hobbies, art, and music that are enjoyed by the patient.  "Listening, expressing feelings, sharing experiences-all highly holistic activities-are integral to linking mind and spirit to the condition of the body" (Engle, 2004).  Spirituality may be found in relationships with people and in the meanings that are in these relationships.

"Unfinished business" can make dying less acceptable and grieving more difficult for family members left behind.  Hospice recognizes that a person who comes to terms with dying experiences a

more peaceful death and that the family goes through a somewhat less complicated grieving process. Many hospice recipients state that a source of relief and comfort is the knowledge that their families will receive ongoing bereavement support (Naierman, 2004).



Individuals who face imminent death deal with the loss of their own lives. They experience various emotional stages that may occur consecutively, overlap or diminish for a time. Research has identified five stages:
♦ Denial, shock, and disbelief;
♦ Anger;
♦ Beginning to accept the reality (bargaining);
♦ Depression, characterized by feelings of hopelessness and despair; and
♦ Acceptance of loss (Kuber-Ross, 1969).

Spirituality may help individuals accept death as they may view it as a continuance of their lives/spirits in another form.

Religiosity and spirituality have different definitions. Residents' religious needs may include having a relationship with God, preparing themselves for death, and participating in the specific rituals and requirements of their religions. Spiritual needs are broader than religious needs. These needs may encompass finding the meaning of one's life, reflecting on life accomplishments, events and disappointments, connecting to important people, and reflecting on nature, art, and music (Cohen and Koenig, 2002). Research shows that religious coping is the most powerful variable among 14 others including race, age, social support, and education when depression is measured (Koenig et al., 1992).

Caregivers can assess how well residents' spiritual needs are being met by asking:
● Do the health care providers listen to their beliefs, faith, pain, hope or despair?
● Are the residents able to express or develop their spirituality through prayer, art, writing, reflections, religious or spiritual readings, rituals, or connections to others and God? (Brown University, 2004)

Spiritual care is *offered*, never imposed, by caregivers. Caregivers' capacity to legitimize the spiritual journey due to their involvement in residents' end of life is powerful. Because of this dimension, caregivers need to be very respectful of people's needs and be attentive to the way people go about looking for answers (Rumbold, 2003). Whether or not residents hold religious beliefs, they all express needs for love, meaning, and life purpose. Spirituality is the core of all religions, and it provides the comfort to which most people turn.

## Palliative Care Supports the Needs of the Family Members

Staff should recognize that families need help as well. Support can be offered to family members in many different ways: time off from caring for a dying family member by assigning a staff person or a resident to sit next to a dying resident's bed side, phone support, advice, or just listening. Family caregivers may be at high risk of getting sick themselves due to immune systems weakened by stress. Staff should be creative with ways to assist families coping with the cost of caring, like a loss of wages. Encouraging their children to accompany them while they visit their loved one in a nursing facility eliminates the cost of hiring a babysitter. Mourning is a complex and very individual process, frequently leading to bouts of intense sadness and feelings of loneliness, guilt, anger, and abandonment. Acknowledgment of these feelings by staff may bring comfort to a mourning person.

*Butterflies are Free* is a program created at the Life Center in Sarasota, Florida. Staff place a journal in the room of a dying resident for staff members to write messages about their love for the person, express a special bond between them, capture favorite memories, or offer a spiritual invitation to the eternal journey. Families are brought snacks and beverages during their time spent with their loved one. Carefully selected books on grieving are offered to family members. The Center invites other residents to sit with the dying person when families cannot be with their loved one. Holding hands and praying with a dying resident is encouraged (Nursing Homes, 2005). Time spent with a dying person helps other residents to say good-bye and begin developing meaningful closure for themselves. Many homes in Kansas try to create a more peaceful environment by providing a private room for the resident and family.
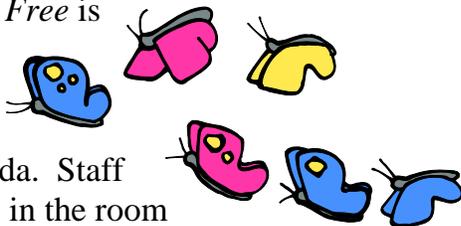
- Staff at Lakeview in Lenexa and at Medicalodge in Kinsley make sure to give a sympathy card to staff members who were close to a resident who passed away. A card also circulates among residents to give them an opportunity to express their feelings, to write down memories of the deceased person, and to say good-bye to the person who touched their lives in many ways. Then the card is sent to the family who may find comfort knowing that their loved one is going to be missed by so many people.

- Lakeview Village offers, whenever possible, a memorial ceremony in the residents' rooms before their bodies are taken from their last home. It allows residents and staff members to pay their last respects and begin the closure process. A deceased resident is escorted by the chaplain and staff in procession through the front door. Such rituals help staff and residents recognize the value of the individual

resident and demonstrates how the facility values its residents.

## Bereavement

Bereavement support is help in coping with the loss of a loved one.  Grieving is a normal psychological process that people connected to a dying resident, such as staff members, family members and friends, go through when a person they love or take care of dies.  Hospice is committed to helping people who are grieving.  It provides an opportunity for spiritual growth to a dying resident and people who are with him or her during the final stage of life (National Cancer Institute, 2005).

Ninety-seven percent of the support that families receive during the process of dying comes from front line staff (Davidson, 1999).  Bereavement support should be part of the care plan of a dying nursing home resident.  This document gives staff confidence and direction to help family members in a palliative situation (Burke & Gerraughty, 1994).

Hedtke and Winslade (2004) propose conversations with the dying and the bereaved through "Re-membering Lives".  The conversations try to find ways in which possible connections are maintained with the dying individual.  When staff at Lakeview Village sends a card filled with many, perhaps unknown, stories about the family member who died, they may promote grieving through "Re-membering Lives" narratives.

> "Healing from grief is not the process of forgetting, it is the process of remembering with less pain and more joy."
> -Unknown

A memorial service and funeral are important in the chain of events that occur after a death.  People who participate in a memorial service will learn about the life of the deceased individual, his or her place in the family, community, organization, and perhaps even nation.  It is a final opportunity to show appreciation and love for the person.



Many nursing homes display pictures of residents who passed away and their favorite objects.  They are powerful symbols and a reflection of a person's life, interests, and values.

- Parkside Homes in Hillsboro holds a memorial service for each resident who dies.  All residents, the family, and friends participate in the ceremony conducted by the minister of the resident who passed away.  Residents have an opportunity to express their sympathy and share memories about the person.  The guest register with comments and memories from the staff is sent to the family.

- Ellis Good Samaritan Center provides the family of a dying person with fresh coffee and cold beverages, and the family is encouraged to request meals through the kitchen. A bedside memorial is held after the resident's death and is open to all residents and staff. The family receives a crystal cross with a candle and personalized note from the staff. They enclose a devotional booklet to help the family members grieve their loss.

- Medicalodge of Wichita gives the family a bible that is placed in a beautifully crafted wooden box. The gift symbolizes respect and memory of the person who passed away.

- Morton County Care Center in Elkhart hangs a wreath and pins pictures of the deceased on a prominent wall where they stay for a few years. A memorial service is held for residents and family members.

- Medicalodge in Kinsley staff put out a sympathy card and a silk rose on the bed of the newly deceased and invite family to come.

All these rituals commemorate residents and help other residents and family members grieve.

## Palliative Care Provides Access to Needed Health Care Providers

This is the time to use a diverse disciplinary approach, well-experienced staff in hospice care, and clergy to visit a dying resident. Trained care providers, doctors, nurses, pharmacists, clergy, social workers, and nurses' aids are all invaluable in providing care to a dying resident (Kansas Life Project).

## Palliative Service Provides Excellent Care at the End of Life

In order to provide excellent service, staff members need to learn about the best ways to care for dying people. Besides education, staff need support when dealing with the emotional pain associated with participation in the dying process. Caring for people at the end of their lives can be emotionally exhausting. Dealing with their suffering on a daily basis may cause caregivers to feel helpless and useless. An orientation in death education that explains the stages of dying, family and staff related issues, and bereavement should decrease staff's emotional and physical exhaustion. When staff are more comfortable with death, they are able to provide better service in this area and meet the needs of the bereaved (Gross, 2003).

Palliative care should encompass all the ingredients so beautifully captured by the Kansas Life Project (1991):

*"Kansans should expect health care providers and caregivers who:*
- *Know that dying is an important time for you and your family.*
- *Offer ways for you to be comfortable and ease pain and other physical discomfort.*
- *Help you and your family make needed decisions if the illness gets worse.*
- *Make sure you are not alone.*
- *Understand there may be difficulties, tears, and painful feelings.*
- *Give you the chance to say and do what matters most to you.*
- *Help you look back on your life and make peace, even giving you a chance to grow."*

## The Death Rituals Activity

What rituals do we conduct at our nursing home in order to help a person die a better death?

_____
_____
_____
_____

What residents' and/or their families' needs do these rituals meet?  Why do we need rituals?

_____
_____
_____
_____

What would you like to introduce that would make death-related rituals more congruent with palliative care principles?

_____
_____

_____
_____

## Holistic Model

All these principles are very important ingredients of palliative care, but they should not be implemented only when a resident is officially diagnosed with a terminal illness.  Hospice-type care can be provided for all permanently placed nursing home residents, including residents with a terminal diagnosis. *End-of-life does not necessarily mean just death; it should encompass the last stage of human life.*

Engle (1998) identified that Minimum Data Set (MDS) and Resident Assessment Protocols (RAPs) have limitations and are not always accurate for a terminal illness diagnosis and determining a six-month month prognosis.  "A hospice referral requires a prognosis that death is expected within six months or less, yet median stay for hospice patients is less than 25 days" (Crow & Werth, 2005, p.1&6).  The insufficiency of current tools prevents providing hospice care to everyone who needs it.  Engle suggests focusing primarily on the "living-dying interval" and the quality of living-dying outcome indicators associated with it, rather than focusing on just the dying interval.

The living-dying interval is the period of time between the knowledge of one's impending death and death itself (Pattison, 1977).  There is no accurate way to estimate one's life duration

(Engle, 1998).  "Lingering expected deaths are associated with frailty in old age" (Gold, 2003, p.22). These people have no reserve defenses.  They may die from simple causes like influenza or decline so gradually that signs of the end of life cannot be clearly defined. The fact is that the majority of people in nursing homes are near the end of life (Gold, 2003). Dr. Meier, a geriatrician from Mount Sinai Medical Center in New York, applies palliative care to any patient at any age, regardless of whether they are expected to die or recover. She recognizes that millions of Americans are now living with multiple chronic illnesses for years before they die, such as dementia, heart disease, chronic lung disease, cancer, and frailty, and it is not possible to say they'll be dead in six months. "Palliative care is optimal medical care for sick people, whether they will live for 10 days or 10 years" (Brody, 2003).

The beginning of the dying process is not one of only medical uncertainty.  It is also evidence of a lack of concepts for this stage of human life.  It is commonly known that most people entering a nursing facility experience a heightened awareness about the imminence of death (Johnson, 2005). An absence of accurate prediction models for death may exclude or delay hospice care for residents and their families.  This is one of the main reasons that hospice-type care should be provided to all permanently placed nursing home residents upon admission (Engle, 1998).

> "The problem of defining when someone can be labeled as dying is a manifestation of the denial of death" (Johnson, 2005, p.40).

Many studies indicate that residents are more concerned with the quality of day-to-day living than dying.  Nursing homes are more about living than dying.  It may be necessary to regard all permanently placed residents as being in the living-dying stage in contrast to hospice patients receiving this type of care in the community.  Consequently, the focus on the living-dying interval will promote quality of living-dying in a nursing home.  This will encompass all the ingredients of palliative care equated with a high quality of living (Engle, 1998).

It is important to note here that the length of stay of residents in nursing facilities is often short.  Data from 2001 shows that 43% of residents were still living there three months after their admission (LaPorte, 2006).  The other residents were either discharged or died. Only 16 percent were still at the facilities a year after their admissions (LaPorte, 2006). Due to this, the time during which residents live in nursing homes should be effectively utilized to help them with their personal growth.

The end of life seen in a broad perspective should be embraced for the

new experiences it brings.  A dying person may experience a heightened need for forgiveness, a deepening love, and a "pervasive sense of gratitude for the experience of life" (Singh, 2000).

A look at the living-dying stage from the perspective of Erikson's theory of development of psychosocial stages will further explain the specific skills and needs of older people.  Erikson viewed a human life in eight stages.  Each stage has its aspirations and challenges, characterized by tensions between an individual and external conditions. As a person ages, he or she enters the stage of generativit**y** during which a person starts manifesting care for the next generation. The important ingredient of this stage is becoming "Keeper of the Meaning".  This task is passing on the traditions of the past to the next generation. This role allows an older person to link the past to the future (Erikson, 1963).
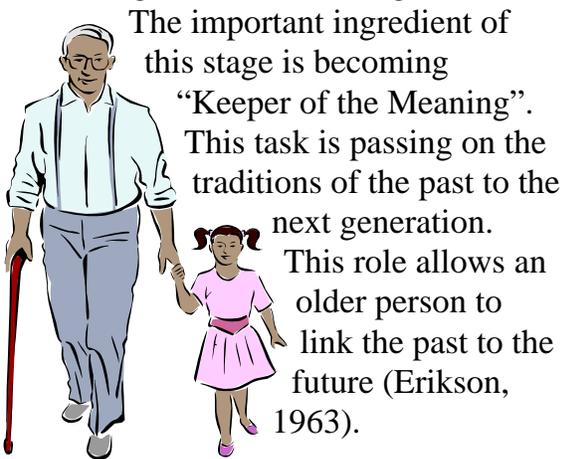
The final stage, integrity, is characterized by "some sense of peace and unity with respect both to one's own life and to the whole world" (Vailliant, 2002, p.45).  An older person reviews life accomplishments, deals with loss and prepares for death.  Erikson believed that much of life is spent preparing for the middle adulthood stage, and the last stage is recovering from it. Perhaps that is because older adults can often look

back on their lives with happiness and contentment, feeling fulfilled with a deep sense that life has meaning and they have made a contribution to life; Erikson calls this feeling integrity (Erikson, 1963). Many gerontologists consider the later years of life as the period when one looks for meaning in one's life to maintain a sense of identity and find peace in the face of one's imminent death.  The National Advisory Council defined this stage as "the witness of a lifetime of experience."

On the other hand, some adults may reach this stage and despair at their experiences and perceived failures. They may fear death as they struggle to find a purpose to their lives. Alternatively, they may feel they have all the answers and end with a strong dogmatism that only their view has been correct (Vaillant, 2002).  This is the final stage of psychological and social development. Failure to deal with it may result in feelings of emptiness (Mackinlay, 2001).

Most people admitted to nursing homes are in the integrity stage of life.  A resident in a resident-centered nursing home is more likely to receive the support he/she needs during the integrity stage than a resident in a medical-model nursing home where the residents are defined by the medical care they need.

> "A nursing home should first and foremost be a home. It is often the last home of a resident's life." (Congress of California Seniors, 2003).

We should never forget that *"It is not about the age. It is about the wisdom. An Elder is a person who is still growing, still a learner, still with potential, and whose life continues to have within it, promise for and connection to the future. An Elder is still in pursuit of happiness, joy and pleasure, and her or his birthright to these remains intact. Moreover, an Elder is a person who deserves respect and honor and whose work is to synthesize wisdom from long life experience and formulate this into a legacy for future generation"* (Barry Barkan, Live Oak Institute).

Applying the principles of palliative care for the dying process from the moment a resident is admitted to his or her new home will help facilitate residents' appreciation for who they are and for their life experiences regardless of their current physical or mental ability. With the holistic approach to the end of life a resident is not just an old person but an Elder. When an Elder is seen in each resident, staff's attitude toward residents will change, as they try to incorporate the principles of Elderhood into the residents' lives.

Barry Barkan and his wife, Debora, two of the founders of the Pioneer Network, have attempted to build "normal life" into nursing homes rather than "a holding tank prior to death." They have introduced the *Regenerative Community* model in their homes. The key of the model is the elders' community. Residents meet for an hour every day. They introduce new people, and they talk about their concerns/joys and the house, share the local/worldwide news, hold memorials for residents who died, plan events, etc. The principle purpose of these daily gatherings is to avoid leaving anyone alone in a room.

The Barkans recognize the importance of a community where elders can share their wisdom and empower themselves with the skills to learn to grow and develop spiritually, emotionally, physically, and intellectually. The skills help elders continue to have meaning and growth in their lives. Being a part of a community is a very spiritual experience; people are connected to each through the power of a circle that gives them meaning, empowerment, mutual support, and the opportunity to learn and be civically engaged (Baker, 2002). The sense of community renews joy in one's life even as aging leads to the end of life. The *Regenerative Community* can be a platform for elders to give and/or share their life stories with their community

members.  This is an excellent vehicle for the introduction of life review, legacies, and unfinished business, whenever it is appropriate.  The model promotes valuing residents for who they are and for their life experience without focusing on their current physical and mental abilities.

The last life stage is the path of possibilities that lie within the aging process, a journey toward identifying meaning, purpose and wisdom at the end of life.  Rabbi Zalman Schachter coined a new term for aging: *sage-ing.*  Its elements are dealing with:

- life completion;
- nourishing ourselves mentally, physically, emotionally, socially, and spiritually;
- engaging in Life Review and Life Repair (forgiveness);
- harvesting wisdom (through life experience); and
- passing on wisdom.

His mission is reclaiming the traditional role of elder that is rooted in the importance of community.  "Sage-ing means acting as a guide, mentor, and agent of healing and reconciliation on behalf of the planet, nation, tribe, clan, and family. "We become wisdom keepers" (Schachter–Shalomi, 1994, p.17).

In a study, Cox, Kessler and Eisner suggest not asking people how old they are but "How many years of life experience do you have?"  The answer brings people pride; they feel more valuable and wise.  They know they can offer and give something to the community (Cox, Kessler, Eisner, 2006).  The Sage-ing concept is congruent with Erickson's life development model, Barkans' Regenerative Community, the Eden concept, and Engel's holistic approach to care that should be the basis of care offered by nursing homes across the country.

Nursing homes with their health-promoting expectations and rehabilitative approach to health care have unintentionally produced a death-denying culture within the nursing home.  Many facilities transfer imminently dying residents to hospitals to avoid taking care of residents during their final hours (Johnson, 2005).  The holistic approach to the care of nursing home residents may help people view death as a natural part of life.

> "Positive aging is not simply avoidance of physical decay and it certainly is not about the avoidance of death" (Vailliant, 2002, p.161).

## 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)

# Projects

Most nursing homes continuously try to increase quality of life both for residents and their families.  These projects should help residents and staff identify various appropriate culture-respecting norms in grieving deceased residents and help residents identify which rituals are meaningful for them and how they would like to be remembered.  The projects will assist residents in becoming elders by passing their life wisdom and experiences to the next generation.  The projects should help both residents and staff discuss their own end of life and issues associated with death.

All of these projects can be done with assistance from residents to help them grieve and to show them that none of the residents are forgotten after death. All these rituals are beautiful activities reflecting love, respect, and the value of each human being's life.  However, they become truly meaningful when they reflect the deceased person's wishes, values, and cultural norms they related to emotionally.  It seems that not too many homes involve residents in discussing their after death ceremonies perhaps due to discomfort discussing the subject.

**1.  <u>The After Death Rituals Project</u>**: This activity is a good platform to discuss residents' cultural rituals.  How is death treated in their culture?  What type of celebration is held following a funeral?  What are characteristic features of funerals in their cultures?  What kind of a behavior or conduct is expected from a grieving family member?

Here are some other rituals to help a person grieve that might interest you.  You may suggest them, when appropriate, to a grieving family member, friend, and also use them at your facility:

1. Turn on a small lamp: Keeping light on is a wonderful way to honor the spirit of a loved one. A lamp can be placed in a window or by a special chair and left lit every night. The light from the lamp can be symbolic of love continuing.

2. Plant a tree: Trees are ever growing. They can be a reminder of life cycles from year to year. Trees are an outward expression of inward growth. Some people like to place a tree in their yard or in a favorite place their loved one liked to visit.

3. Make a memory box: Take a shoebox or another small box. Decorate it with items that hold memories. Inside the box put things that remind you of your loved one. You might want to add a little note explaining why a certain item is so special. Keep the memory box for yourself, or pass it on to a person who might appreciate it.
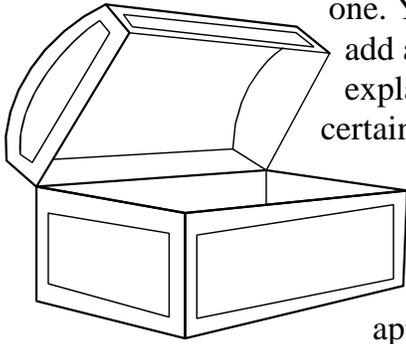
4. Have a special chair with a flower upon it remain empty to symbolize your loved one's continuing presence at your events" (Healthy Minds. Healthy Lives).

*Assessment and evaluation:* During or following this activity, ask residents if this is a respectful and meaningful way to remember a deceased resident's life.

What kind of a ritual will they choose for themselves and why? Do they want other residents and staff to participate in the ritual?

## 2.  **The Obituary Activity Project**:
While working on an obituary for a deceased resident, you can ask residents how they want to be remembered by the ones left behind.  This project should be done in a small group, preferably one on one.

Help staff and residents write stories about the person who died.  Perhaps you can find a picture of the resident when he or she was engaged in favorite activities

at your home.  Or you can ask a family member for a copy of a picture.  Hand the residents and staff old magazines and scissors.  Help them find pictures or words that remind them of the deceased resident or symbols that reflect who the resident was.  Ask the participants what they want to include in the departed resident's obituary.  Put the stories, pictures, and photos on a board. The color of the board can also symbolize the residents.  Perhaps blue was their favorite color or green can symbolize their love for nature.  Place the board for everybody to see for a few weeks or months.  Some facilities keep pictures of their deceased residents for an entire year or longer.

*Assessment and evaluation:*  Ask residents what pictures, symbols, or words will reflect their personality and life.

Do they have different ideas to help residents remember the one who passed away?  What should a nursing home do to commemorate them after they die?

## 3.  **The Review Life Project**:
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
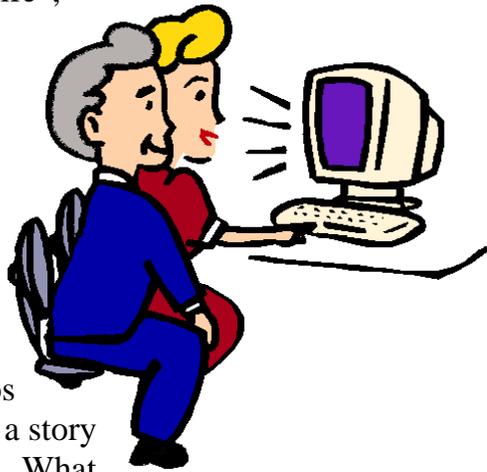
will be comfortable telling a life story to a few staff members. In this case, the project has to be well managed by these staff members. Review what has been written prior to resuming collection of new memories. Staff should establish a regular meeting time with a resident to emphasize the importance 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?

# Post-test

*The pre-and post-tests included with this module are optional. The questions provide
information about the material to be covered and can be used for learning self-evaluation.*

1.  Which of the following statements are true for palliative/hospice care principles?
    A. Goals, likes, and choices of the dying person are followed.
    B. Medical, emotional, social, and spiritual needs of the dying person are met.
    C. Needs of the dying person's family are met.
    D. The dying patient has access to needed health care providers.
    E. Excellent care is provided to the dying person.
    F. All of the above.

2.  What percent of deaths occur in nursing homes in the U.S.?
    A. 5-7%
    B. 10-12%
    C. 38-42%
    D. 20-25%

3. What is median length of hospice care for a dying person?
    A. Sixty days
    B. Three and a half months
    C. Six months
    D. Twenty-five days

4.  An advance directive is:
    A. A legal document identifying division of inheritance.
    B. A description of what treatments are acceptable to a person when he/she is not
       able to make a decision due to an advanced disease.
    C. One of the documents required upon admission to a nursing facility.
    D. None of the above.

5.  What are the benefits of spiritual care offered to a dying person?
    A. Helps him or her find meaning at the end of life
    B. Helps him or her accept death
    C. Helps him or her grow as a person
    D. All of the above

6. Which definition of Elder is false?
   A. An older member of a Native American tribe
   B. An older community member to whom people come for advice
   C. The oldest person in a group
   D. A school child

7. The last stage of a person's life is usually characterized by:
   A. A desire to pass one's life experience to a younger generation.
   B. A review of one's life.
   C. Preparation for one's death.
   D. Despair if a person has not accomplished his/her life goals.
   E. All of the above.

8. Which of these statements are true?
   A. Depression is a normal part of the dying process.
   B. Most people prefer to die alone.
   C. When a loved one is dying in a nursing facility the family receives the majority of its support from frontline workers.
   D. Most people are not comfortable talking about death.
   E. Both C and D

9. Which of the following describes a Regenerative Community?
   A. An emphasis on energy recycling
   B. An emphasis on the importance of community
   C. All community members contribute work for the good of all
   D. An emphasis on physical fitness

10. What are possible reasons for residents to talk about their past?
    A. A resident's short-term memory span is poor.
    B. A resident likes to reminisce about his or her past.
    C. A resident tries to identify the meaning of his or her life.
    D. A resident is very critical of the present time.
    E. All of the above.

## Pretest and Post-test Answers

1. F
2. D
3. D
4. B
5. D
6. D
7. E
8. E
9. B
10. E

# Resources for Palliative Training
From Caring for Ages Nov. 2004

Education on Palliative & End-of-Life Care
http://epec.net

National Hospice & Palliative Care Organization
http://nhpco.org

American Academy of Hospice & Palliative Medicine
www.aahpm.org

The Center to Advance Palliative Care
www.capc.org

American Association of Colleges of Nursing
www.aacn.nche.edu/elnec

End-of-Life Nursing Education Consortium Project & End-of-Life/Palliative Care
Education
www.aacn.nche.edu/elnec

Hartford Center of Geriatric Nursing Excellence
www.nursing.upenn.edu/centers/hcgne/palliativecare.htm

Promoting Excellence in End-of-Life Care (University of Montana)
www.promotingexcellence.org

# Resources for Pain Management

Kansas Foundation for Medical Care
http://www.kfmc.org/

Kansas Advocates for Better Care
http://www.kabc.org/

The LIFE Project
http://www.lifeproject.org/home.htm

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