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# END-OF-LIFE NURSING CARE: ESSENTIAL CONCEPTS

Course # 2019  
2 Contact Hours

Author: Angeline Bushy, PhD, RN, FAAN

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# End-of-Life Nursing Care: Essential Concepts

## Disclosures

### Description

Authors: Angeline Bushy, RN, CNS, CHN, Ph.D | Shelda L. Hudson, RN, BSN, PHN

The goal of this course is to present the essential concepts of palliative care, with emphasis on emotional, psychosocial, spiritual and family issues; pain management and the rights of the patient to self determination and decision making are also discussed.

Course objectives include:

Outline ways to address the psychosocial and spiritual concerns of the dying client.

Define pain and pain tolerance.

List factors that influence pain perception, in respect to culture, gender and age.

### Criteria for Successful Completion

After reading the material, complete the online evaluation. If you have a Florida nursing license or an electrolyte license you must also complete the multiple choice test online with a score of 70% or better. Upon completion of the requirements you may immediately print your CE certificate of completion.

### Accreditation

California Board of Registered Nursing Provider No. CEP 1704.

This course has been approved by the Florida Board of Nursing No. 50-1408.

### Conflicts of Interest

No conflict of interest exists for any individual in a position to control the content of the educational activity.

### Expiration Date

This course expires October 29, 2021.

## About the Author

**Dr. Angeline Bushy, PhD, RN, FAAN,** Professor and Bert Fish Endowed Chair in the College of Nursing, at the University of Central Florida. She has practiced in a variety of community and rural health care settings, including clinical as well as educational settings. She has published extensively, presented internationally and nationally on community and rural healthcare nursing issues.

## Purpose and Goals

The goal of this course is to present the essential concepts of palliative care, with emphasis on emotional, psychosocial, spiritual and family issues; pain management and the rights of the patient to self-determination and decision making are also discussed.

## Learning Outcomes

Upon completion of this course, the motivated learner will be able to:

1. Define and characterize palliative care.
2. State the role of palliative care and symptom management in end-of-life care.
3. Outline ways to address the psychosocial and spiritual concerns of the dying client.
4. Define pain and pain tolerance.
5. List factors that influence pain perception, in respect to culture, gender and age.
6. Outline non-pharmacologic intervention options available for pain control and palliative care needs.
7. Name the ways that advanced directives play in rights to self-determination and enhancing the quality of life, at the end of life.

## Introduction

End of Life Care? Palliative Care? These two terms often are interchanged in the literature. How does palliative care relate to life and end-of-life and vice versa? In respects to end of life care, many healthcare professionals (HCPs) subscribe to the notion that death is simply another dimension of life - a transition of living. This perspective of death as a major life transition should be the focus of care for a client in the last stages of life (AHRQ, 2018).

The goal of palliative care is to relieve the symptoms of a disease that result in human pain and suffering; however, palliative care is not expected to cure the disease. This continuing education program focuses on the activities of HCPs who are involved in providing this type of care to a client (patient). (Please note; in this continuing education program the terms "client" and "patient" are used interchangeably.) For this program, the focus is on assisting and providing support to a person who is in the end stage of life, as well as to his or her family system. In all cases it is the patient (client) and their family system who establish priorities for care: the role of the HCP is to support the family system in achieving their unique goals. The concept of "family system" is broad and encompassing; and, includes the client's significant other(s), immediate and extended family members, friends, and in some

instances even the community. Each person defines who is included in his or her family system, and this group will vary from person to person (NCHPC, 2018).

In general HCPs, in particular direct care-givers, are in an ideal position to assist, and even provide alternative perspectives to a person in their care; and, allow the client to be open about personal feelings. Opportunities for meaningful interactions can be especially evident when administering personal care to the client in their home. A certain intimacy can be established while assisting a person with the usual and ordinary things of life such as preparing meals, doing housekeeping activities, and completing personal care. An outcome of this course is that the HCP will learn to be more comfortable with patients with terminal illness and be able to put into practice effective and compassionate end-of-life care (Bar-Sela, et al, 2018; Griffith, 2018).

## Quality Palliative Care

Palliative care and symptom management are the essence of care for a client experiencing end stage disease symptoms. They are directed toward promoting a high quality of life, relief of suffering, and supporting a peaceful death. They encompass the active and total care of individuals with a disease that is not responsive to curative treatment (AHRQ, 2018; NCHPC, 2018).

Diagnostic procedures and special treatments such as chemotherapy, radiation, nutritional augmentation, pharmacotherapies, and in some cases even surgery, may have a place in palliative care. These interventions are ordered by the physician when the benefits of relief of symptoms outweigh the disadvantages of a patient not having palliative care interventions. The goal of any intervention in palliative care is to improve the quality of life for the person by managing the symptoms as opposed to controlling or curing the disease.

**"The only courage that matters is the kind that gets you from one moment to the next."**

**– Mignon McLaughlin**

Palliative care focuses on the relief of suffering when the underlying disease cannot be cured. Suffering is described as a state of severe distress that often is associated with events that threaten a person's intactness as a human being. Hence, suffering is viewed more broadly than simply experiencing physical pain. Rather, the whole person experiences suffering: having pain in the mind and spirit as well as one's body. Moreover, the physical

symptoms will vary in patients with different diagnoses, the affected body systems, the progression of an end stage disease; and, the impact of these factors on the individual. For example, nearly 75% of people with cancer experience pain at some time during their illness. But other conditions produce pain as well, including heart disease, AIDS, decubitus ulcers, and neuropathy. Different interventions may be needed to manage the pain experienced by different clients with these different diseases (Chi, et al, 2018; Dahlin & Coyne, 2018; Dobrin, et al, 2018)).

In addition to pain, there may be other physical symptoms experienced by the client receiving palliative care. For example:

- Neurological symptoms including seizures, paralysis, or changes in mental status such as lethargy, confusion, agitation, or hallucinations; sensory and perceptual changes.
- Cardiovascular symptoms such as edema, syncope, hemorrhage, or angina.
- Respiratory symptoms such as dyspnea, cough, or congestion.
- Gastrointestinal symptoms such as nausea, vomiting, anorexia and cachexia, constipation, diarrhea, prolonged or continuous hiccups.
- Genitourinary symptoms such as incontinence, retention or dysuria.
- Musculoskeletal symptoms such as weakness, fatigue, pathologic fractures, contractures and spasms.
- Integumentary (skin and mucous membranes) symptoms such as pressure ulcers, ulcerative lesions, dry mouth, oral lesions, infections and pruritus.

Consequently, in addition to assisting with or providing routine activities of daily living during care, special therapies may be ordered by the physician to relieve or manage a patient's symptoms. For instance, nutritional, physical, occupational, or speech therapy may be ordered for persons with a chronic disease or debilitating condition to maintain a certain quality of life during the end stages of the condition. Such interventions may also help to maintain a greater degree of mobility or enable one to participate in activities of daily living for a longer period of time. Medical supplies and durable medical equipment also can be helpful in palliative care and symptom management, such as hospital beds with special features; oxygen, intravenous, and enterostomy therapies; and wheelchairs and other comfort devices. In addition to improving comfort, durable equipment and medical supplies can help to provide a safer environment for the client as well as caregivers (Brooks, et al, 2018; Forbat, et al, 2018; Kadivar et al, 2018).

## Management of Specific Symptoms

Symptom management in many cases is the most important activity in providing care to a client. Symptoms will vary from person to person, and his or her particular health problems or diagnosis. Likewise, the symptoms will change in intensity, frequency and duration as the disease progresses. Carefully listening to what the client is telling you, observing and assessing for changes from the baseline status, then intervening early on can go a long way to managing symptoms.

Symptoms that are addressed by palliative care interventions include intense physical and emotional discomfort, nausea, vomiting, anorexia, pain, skin breakdown and decubitus ulceration, urinary and bowel irregularities, and respiratory problems. If these cannot be managed at home, short-term inpatient care may be provided for symptom control, respite care, or hospice care services when death is imminent (Smith, et al, 2018).

## Emotional and Communication Support

Palliative care interventions must be also take into consideration related occurrences of depression, anxiety, and sleep disorders that can contribute to physical or emotional symptoms. Furthermore, unique psychosocial issues accompany terminal illness. Emotional responses such as denial, anger, sadness, acceptance, and hope may vary from day to day and may differ between the client and various members of the family. The coping skills to deal with the loss of the loved may be limited, or dysfunctional, in some family systems. Even family systems that have effective coping abilities may find relationships strained at some time during the progression of terminal illness in a family member (Wen, et al, 2018).

Obviously, one of the most critical components of palliative care is effective communication between and among the client, caregivers and family members. Caregivers involved in terminal care must be aware of the opportunity and carefully listen for an opening for communication with the client. Most persons at the end of life want to talk about the process of their own death with loved ones. Oftentimes, family members feel extreme discomfort with the topic, and are unable to participate in discussions of death and dying. In these situations, HCPs can lead the way and assist the family system to feel that it is okay to talk about death and dying within the family and the HCP (Schoonover, 2018).

Many times, actually saying the words "death" and "dying" provides an opening for the HCP to begin communication on the topic.

If the HCP is comfortable with those words, that in and of itself can help others to feel more comfortable talking about highly sensitive topics of death, loss and grieving. In one case Mary, 72 years old, had end stage cardiac disease and was having trouble making a decision about continuing to live at home. Mary wanted to remain at home but her family was very concerned about her living alone. When asked what she believed their real concern to be Mary said, "I think my family is afraid they will come into my home and find me dead." When asked if she was afraid to die at home or even alone, her response was, "Heavens, no! This is where I want to spend my last days. I want to die where I lived for the last 50 years with my husband and children. My husband died in our house 7 years ago. This is where I belong."

Her HCP informed Mary, the client in this case, validated that she was capable of making her own decisions about end of life care. To help reduce the family's anxiety, Mary agreed to carry a portable phone with automated dialing for quick access to her family and doctor. This strategy reassured the family, and allowed Mary to live at home even with the seriousness of her illness. Subsequently, upon making a routine home visit, the HCP found Mary deceased in her own bed. In essence, the care plan for Mary focused on assisting her to live and die in the manner she desired.

**Be strong and courageous. Do not be afraid or terrified because of them, for the Lord your God goes with you; He will never leave you nor forsake you.**

Moses, Deuteronomy 31:6

## End-of-Life Spiritual Needs

Often when HCPs consider spiritual care, or the spiritual needs of clients, they focus on providing opportunities to participate in some specific religious ritual, such as the sacrament of communion or last rites. Or, the HCP offering to call the person's rabbi, priest, or minister (Bybee, 2018; Jang, et al, 2018; Webb, et al, 2018).

Yet, spiritual needs can be more concretely and broadly defined, if one will move from looking at the symbols of a person's relationship to God to the essence of that relationship itself. The basic spiritual needs of all persons are:

1. the need for meaning and purpose
2. the need for love and relatedness
3. the need for forgiveness

Throughout history mankind has searched for the meaning of life, and this search has

been the primary motivation for many of life's richest and most satisfying experiences. For many, ultimate hope and meaning comes from a relationship with God. This bond is especially important for the person searching for meaning in the face of death. Reliance on people and worldly achievements falls away as they will all be left behind, and the focus is increasingly on the unknown future. Those who have a relationship with a Higher Power, Supreme Being or, God can reflect and contemplate their future with hope and a sense of peace. (Note: For the sake of brevity, only the term God will be used in this program.)

The need for love and to be in relationship with others is also a profound spiritual need. The dying person is no longer in a position to earn love from other people or tries to meet the conditions required to obtain or maintain their love. The only true and lasting source of unconditional love is God, and the dying person may turn increasingly toward the Higher Power for that love. Guilt is one of the biggest burdens of one's life, and it comes from the sense of failure to live up to expectations, either one's own or those of others, or of God. The dying person needs time to settle differences and to receive forgiveness from God and from others if he is to die in true peace. To ease suffering, sometimes a dying person may need permission to pass on from this life from one or more family members.

Is it appropriate for the HCP to be interested and involved in meeting the spiritual needs of the client? Absolutely! When assessing the spiritual needs of the dying, it is important to evaluate each situation carefully, using the nursing process. Spiritual care should not be given haphazardly or with pat answers. Each individual is unique, and so are his needs (Lehman et al, 2015).

Healthcare professionals may use their own spiritual selves in a therapeutic way to address the spiritual needs of the client. To do so, the healthcare professional affirms each patient as a person worthy of our time and involvement, and relates to each in a supportive, caring way. In essence this is a process of 'being' as opposed to 'doing'. To relate to people in this way means that the caregiver must be confident in who she is and what she believes, and this requires facing and resolving her own issues regarding death and dying.

Therapeutic use of self involves skills such as listening, empathy, vulnerability, humility, and commitment. It is a difficult task, but it can be accomplished with faith, education, and practice. The HCP must be willing to continue in the relationship as long as that person needs spiritual support. He will experience pain and grief when he gets involved with his clients in this way, but there is tremendous reward in

knowing that one has helped the dying person through one of the most difficult and stressful times of life (DiGiulio, et al, 2018; Meziane, et al, 2018).

"I know it sounds corny, but somehow the sun seems brighter and the grass seems greener these days. I always loved to walk in the park near our house, but often I was too busy to find time. Now I still have the same job and home obligations, but I find time to walk in the park almost every day. I know they haven't done any landscaping there recently, but every tree and little bush looks more beautiful than ever. I enjoy watching the seasons change, treasuring each one, but also looking forward to the next. Lest you think I'm some kind of saint, you should know that I have terrible crying jags at times, get into loud arguments with my husband, and drive the kids crazy about keeping their rooms neat. Still, a postcard or a phone call from a friend I haven't seen for a while seems very precious. I guess you might say life suddenly seems sweeter now that I know it is no longer guaranteed."

A cancer patient

## **Pain Management: Pharmacological and Complimentary Therapies**

Pain management is an important component of palliative care. In recent years major contributions have been made to nursing research literature regarding protocols for pain relief. The holistic view of pain and its management includes attention on the part of the caregiver to physical, emotional, social, and spiritual needs. Adequate availability and doses of analgesics, including narcotics; around-the-clock scheduling; and the use of co-analgesics and other non-drug interventions have made the control of pain an attainable goal. Throughout the care process, the client is central in making decisions about pain management. Judicious use of prescriptive and non-prescriptive drugs can greatly enhance the quality of life by providing relief from pain and other discomforts such as nausea, vomiting, and diarrhea (AHRQ, 2018;

NCHPC, 2018).

Analgesia includes not only drug therapy, but also non-pharmacological interventions such as imagery, massage, therapeutic touch, music therapy, and meditation. The goal of therapy is to keep the client comfortable, as defined by the client, without overly clouding mental and cognitive functions necessary to the client's participation in the activities of daily life. Fears of addiction to narcotics frequently are a concern to clients and families as well as healthcare professionals. Thus, teaching about pain management and facilitating the expression of beliefs about the use of medications are critical interventions if these are to be used effectively in palliative care and symptom management.

In fact, the American Pain Society suggests that pain rating be treated as the fifth vital sign (in addition to blood pressure, pulse, respiration, and temperature). Nurses in particular, and HCPs in general, can address and manage this aspect of care through assessment, planning, intervention, education and counseling of the patient and family system. As a basic scientific definition, pain is a sensation caused by some type of noxious stimulus. From the behavioral aspect, pain is a pattern of responses that function to protect an individual from harm.

The World Health Organization (WHO) has devised a simple, widely used, and effective approach to pharmacotherapy for cancer pain. The five essential concepts in the WHO approach to drug therapy of pain are:

- By the mouth.
- By the clock.
- By the ladder.
- For the individual.
- With attention to detail.

It has been shown to be effective in relieving pain for approximately 80-90 percent of patients with cancer. Called the WHO Pain Ladder, this approach incorporates the concept of an analgesic ladder, a rational, stepwise approach to pain management. For details contact the WHO at <http://www.who.int/cancer/palliative/painladder/en/>

Measures of client comfort and function should be visible to HCPs as well as members of the family system on a documentation record, such as a bedside flow sheet specifically designated for rating pain. Transparent information will provide an assessment of the success of the pain control regimen and also remind the caregiver that ratings above a specified number require intervention. Whether or not the agreed upon goal has been achieved should also be routinely reported at the change of shift, along with other information about the person's status such as vital signs (AHRQ, 2018; NCHPC, 2018).

## Factors Related to Pain Perception

Certainly people of all ages are capable of feeling pain. Two particular age groups with special needs include children and older adults. Nonverbal children will not be able to articulate the presence of pain, nor describe its characteristics. The practitioner must be alert to nonverbal cues such as excessive crying, grimacing, and restlessness. The other age group with special needs includes the older adult. Many older adults assume that pain is a natural part of aging; this is untrue. What is true is that the incidence of disease and illness increases as we age and pain is a common accompanying symptom. Practitioners need to inquire about and then explore older adults' areas of pain. Treatment of the diseases and illnesses present is of utmost importance in achieving pain relief (Brooks, et al, 2018; Cresp, et al, 2018; Jang, et al, 2018).

Emotional state affects one's perception of pain level. Any additional stressors can aggravate the pain experience. The interconnectedness of thoughts, feelings and beliefs plays a part in pain perception from an emotional standpoint. Research has shown that people experience more pain when they focus on it, are told to expect one thing but experience something different, expect a high level of pain, and are tense and under stress. It has been theorized that structures in the brain are closely involved with the emotional aspects of pain perception. It is believed that stimuli are filtered through the limbic-hypothalamic system and that the frontal cortex influences rational interpretation and response to pain. Though physical pain reception is a universal human phenomenon, people experience different pain thresholds and tolerances. Pain tolerance refers to the lowest level of stimulation at which a person will stop or seek to stop the stimulus. Pain is highly individualized; differing from person to person and from situation to situation. Many times anxiety is also present with pain, causing an increased perception of pain intensity. Other psychological factors affecting pain include fatigue and depression (Chi, et al, 2018; Dobrina et al, 2018).

In respect to gender, in the American culture men have typically been socialized to deny or conceal their pain, while women are often encouraged to be demonstrative with their reaction to pain. Some researchers have theorized that estrogen is instrumental in regards to modulation of pain sensitivity. Others have demonstrated that the physical and emotional experiences of pain are similar for both genders, while it is the expression that often differs. Nonetheless, very few studies support gender differences in pain threshold.

## Ten Commandments for Friends and Family

1. Don't give me medical advice.
2. Don't keep asking me how I feel or telling me how I should feel.
3. Don't tell me about other patients who haven't made it.
4. Don't belittle my problem or give false reassurance.
5. Don't avoid me, but be available.
6. Listen to me when I want to talk, and ask me for advice about matters in which I'm knowledgeable. I have a lot to contribute even though I'm sick.
7. Sometimes just sit quietly with me. You don't have to talk constantly to be a comfort.
8. Don't let me feel abandoned, but realize that sometimes I just need to be alone.
9. Always be hopeful for me. I need your reassurance.
10. Provide spiritual support.

— Paul Johnson

Other aspects of pain perception are associated with cultural and environmental factors. When assessing for pain consider factors such as: Is the patient generally vocal or quiet and does he seek and trust the healthcare environment? For the patient who is quiet or distrustful of health care, you may need to actively elicit more information and work to establish trust before you can get an accurate pain assessment.

Family and social support are usually helpful to patients when dealing with pain. Often patients have their own strong support systems already established and find this helps them to manage the emotional aspect of pain. Sometimes the practitioner needs to assist patients to utilize or even establish support systems.

Many people assume that those who experience pain like to be alone but this is not always true, particularly for those that experience chronic or episodic, recurring pain. Studies have shown that when people do not have adequate social support, or perceive insufficient support, they have more complaints of pain and reduced psychological well-being. Formal support groups have been established for many circumstances and HCPs can be instrumental in connecting patients to these resources.

## Complimentary Therapies and Non-Pharmacologic Interventions

Along with prescribed medications there are also non-pharmacologic options to control pain. Often these intervention are used to complement pharmacologic options (i.e., complimentary therapies). Advantages of

using non-pharmacologic methods include the most do not require a prescription or any special equipment. However, always make sure an intervention is appropriate and safe for each patient situation before implementation (AHRQ, 2018; NCHPC, 2018; Rawlings, et al, 2018).

Complementary non-pharmacologic interventions include relaxation and guided imagery, which are often used concurrently. Relaxation can be as simple as focusing on one's breathing to control tachypnea or mentally concentrating on a pleasant thought or scene. Patients can also be taught to progressively contract and then relax various muscle groups, usually in a sequential pattern, such as from neck to toes. Meditation is a form of relaxation. Relaxation and guided imagery are thought to counterbalance the "fight or flight" response the body often activates in response to pain. As a result of using these techniques the body often experiences a reduction in skeletal muscle tension, decreased vital signs, lowered metabolic rate, and reduced oxygen consumption.

Cutaneous stimulation can be used to eliminate pain as well. Techniques that use cutaneous stimulation are massage, acupuncture, hot and cold applications, and transcutaneous electrical nerve stimulation (TENS).

Lastly, never underestimate the value of patient and family education. A well-informed patient and his or her family, usually is the most effective to assist the patient able to cope with the pain. The HCP should not be the only person with the appropriate information on pain and its treatment. Certainly, in today's information explosion society, patients may present with a plethora of information;

however, accessing extensive information is not synonymous with being adequately and appropriately educated and informed. Beyond instructing patients about pain and treatment options, HCPs may need to access correct and current information from reliable websites; then subsequently addressing, clarifying and correcting misinformation for both the patient and family members (Bybee, 2018; DiGuillo et al, 2018; Karbasi et al, 2018)

## JCAHO Standards

The Standards were developed by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) as guidance on pain management for healthcare organizations. Patients facing death need respectful, responsive care. The responsibilities of caregivers include managing pain aggressively and effectively, and responding to the psychological, social, emotional, spiritual, and cultural concerns of the patient and the family.

Additional information on these standards may be obtained from the Joint Commission on Accreditation of Healthcare Organizations, One Renaissance Boulevard, Oakbrook Terrace, IL 60181; Phone: 877-223-6866, or from their Web site at [http://www.jointcommission.org/topics/pain\\_management.aspx](http://www.jointcommission.org/topics/pain_management.aspx).

## The Role of Advance Directives

In recent years, it has been increasingly recognized that an individual has the right to self-determination not only with regard to activities during life, but also in choosing services that will enhance the quality of life during her final days. The person may have chosen an executor, made decisions regarding disposition of personal property, and provided loved ones with information about specific concerns and intentions. An important part of this process is the preparation of advanced directives that may include a living will and a durable power of attorney for health care decision-making in the event of incapacitation. If the person decides that he does not want to be maintained by gastric feeding or mechanical ventilation, then those decisions can be conveyed to the physicians and others involved in his care (Medline Plus, 2018).

Many individuals at the end of life have reported considerable comfort in knowing that they have expressed their wishes and are to be allowed a death with dignity according to those wishes. Healthcare professionals can assist their patients to achieve this level of peace by encouraging the preparation of advance directives.

HCPS should be committed to providing care to the whole person throughout the life

span, and to maintaining a holistic perspective on the needs of the person in their care. What could be more important than gathering all the HCP's personal strengths and professional skills to provide caring support to those facing one of life's greatest transitions?

## Key Points in Palliative Care

In late 2013, The Institute for Clinical Systems Improvement (ICSI) released new guidelines for treatment of palliative care issues. Major recommendations include clinical highlights and key points for healthcare professionals including:

- Planning for palliative care should begin early in the patient's journey of a serious illness. Family members should be included in developing the treatment plan for a patient. Where palliative care consultation is available, referral to this service should be considered early on in the patient's care if there are complex needs. Primary care clinicians should begin palliative care planning early through palliative care conversations with their patients.
- Health care providers should complete a systematic review of patients' palliative care needs and document patients' goals for care and advance directives.
- Suffering is common in this patient population. It commonly presents itself in physical symptoms; thus, controlling symptoms to maximize patient comfort is a cornerstone function of palliative care. Also important are the recognition, assessment and management of non-physical areas of suffering that are important to the patient. These include cultural, psychological, social, spiritual, financial, ethical and legal issues. Where available, consultation with palliative care specialists should be considered for all of these symptoms.
- The ability to address these issues depends on the quality of communication with patients and families. Setting realistic goals of care and providing realistic hope are essential. Engaging patients in decisions about their care increases their involvement and satisfaction. Shared Decision-Making (SDM) is one method to engage patients.
- Palliative care (sometimes referred to complimentary therapies) usually are compatible with most medical treatments.
- Health care providers play an important role in the grief and bereavement processes by supporting the patient and family throughout the course of illness and following the patient's death.

Conditions that may prompt palliative and complementary therapies include chronic illnesses and disabilities, failure to thrive, cancer,

heart disease, pulmonary disease, dementia, liver disease, renal disease, neurologic disease such as stroke, Parkinson's, amyotrophic lateral sclerosis (ALS), multiple sclerosis (MS). For more information on these conditions refer to the original guideline document. Many residents in long-term care facilities have these conditions; therefore, should be assessed for palliative care (AHRQ, 2018).

## Initiate Discussion About End of Life Care and Palliative Therapies

The ability to frankly discuss and plan with patients and their families is as important as any other medical interventions. Practice and experience with discussions about end-of-life decisions and palliative care will improve providers' skill and comfort levels (NCHPC, 2018; Brooks et al, 2018).

Many providers feel they lack confidence and experience in discussing with patients the issues and decisions that come with having a progressive, debilitating illness - specifically recommendations about palliative care and hospice services.

There are several excellent mnemonics available to help providers increase their knowledge, practice examples of these discussions, and generally obtain a better understanding of the emotions, questions and problems that may arise with patients and families at this time in their lives.

The **mnemonic** below can be used to help prompt a successful conversation with patients and families:

**ABCDE** (Advance preparation, Build a therapeutic environment/relationship, Communicate well, Deal with patient and family reactions, Encourage and validate emotions) (AHRQ, 2018; NCHPC, 2018; Medline Plus, 2018)

**Advance preparation:** Obtain the patient's medical information and test results, if possible, so that you are fully aware of the situation. Mentally rehearsing the way you wish to present the information and options can give you a sense of how the conversation may go. Remember to individualize your approach for each given patient based on how much they know at that point and how they prefer to receive information. Make sure that you have an appropriately private location in which to have the discussion.

**Build a therapeutic environment/relationship:** Try to find out how much the patient and family understands, how they want to be told (bluntly, gently, etc.), and how much they want to know at that time.

- “If this condition turns out to be something serious, are you the kind of person who likes to know what is going on?”
- “Would you like me to tell you the full details of the diagnosis?”
- “If your condition is serious, how much would you like to know?” If the patient indicates that he/ she does not want any information, it is important to “leave the door open.” For example you may say, “That’s OK. If you change your mind, at any time, please feel free to talk to me or one of my colleagues.”

Have family members or friends present as per the patient’s preference, and take time to learn names and relationships of each support person present. Use touch and humor where appropriate, taking into consideration your relationship with the patient. Reassure the patient of your availability, set up follow-up appointments, and contact other providers about the situation where appropriate.

**Communicate effectively:** Ask the patient and family members if they have any questions. Speak truthfully but compassionately and avoid using medical terms or euphemisms. Say the words cancer, dying, death, etc. Don’t rush the process; allow time for silence, tears and questions. Remember that the patient may not retain much of the information given past that of the diagnosis or prognosis. Repeat important points and write things down. Think out loud; help the patient and family feel they are part of the team.

**Deal with patient as well as family reactions:** Be sensitive to the emotional reactions of the patient and family. Recognize that denial, blame, intellectualization, disbelief, and acceptance may be present to varying degrees and time frames. Watch for signs of depression and suicidality in subsequent visits. Be empathetic. Crying may occur but make sure that your tears are empathic in nature and not reflective of personal issues on your part. There may be anger from the patient and family about care received from you or another colleague; resist becoming defensive or argumentative about these issues. Try to deal with that particular patient’s and family’s cultural and ethnic norms.

- “I was probably raised differently than you. Can you tell me how your family deals with these situations?”

Encourage and validate emotions of the patient and family members: Offer realistic hope. This may not involve cure, but can encourage symptom control, dignity and peace at the time of illness/death. Discuss treatment options and arrange for follow-up to put those options into action. Talk with the patient about what this means for him/her, and what needs outside of the traditional medical scope he/she may have.

- “I know this is not what you wanted

to hear.”

- Don’t say, “There is nothing more we can do;” instead say, “What we are going to focus on now is (comfort, pain relief, etc.).

Patient and family reactions to serious illness and decisions about end-of-life care are influenced by numerous factors. For more information this Guideline can be accessed on the National Guideline Clearinghouse website, key search Palliative Care.

## Web Sites, Organizations and Projects

### Caregivers.com

Bridges the distance between aging parents and adult children by providing actionable information about products and services. <http://www.caregivers.com>

### Before I Die

A Web site covering a program that explores the medical, ethical, and social issues surrounding end-of-life care in America today <http://ritualfields.com/project/before-i-die/>

### Compassionate Friends

Assists families in the positive resolution of grief following the death of a child. <http://www.compassionatefriends.org>

### AACN End-of-Life Nursing Education Consortium

The End-of-Life Nursing Education Consortium (ELNEC) offers courses for undergraduate faculty, clinical end-of-life care educators and other continuing education/staff development educators. The ELNEC project, a comprehensive, national education program to improve end-of-life care by nurses.

<http://www.aacnnursing.org/ELNEC>

### Institute for Clinical Systems Improvement (ICSI) – Palliative Care

This guideline will assist primary and specialty care providers in identifying and caring for adult patients with a serious (potentially life-limiting, life-threatening or chronic, progressive) illness who may benefit from palliative care.

[https://www.icsi.org/about\\_icsi/legacy\\_work/palliative\\_care/](https://www.icsi.org/about_icsi/legacy_work/palliative_care/)

### Robert Wood Johnson

## Last Acts Initiative

A campaign designed to improve care at the end of life, bring death-related issues out in the open and help individuals and organizations pursue better ways to care for the dying.

<https://www.rwjf.org/en/library/research/2002/10/assessment-of-last-acts-r-program-provides-recommendations-for-.html>

### Legacy.com

Celebrating life stories in words and pictures for now and for the future.

<http://www.legacy.com>

### Medicare Rights Center

A non-profit organization offers answers to questions about Medicare, describes education and services, and provides news and publications

<http://www.medicarerights.org>

### National Family Caregivers Association

A grassroots organization created to educate, support, empower and speak up for those who care for chronically ill, aged or disabled loved ones.

<http://www.thefamilycaregiver.org>

### National Hospice and Palliative Care Organization

A nonprofit organization representing hospice and palliative care programs and professionals in the U.S.

<http://www.nhpco.org>

### Hospice and Palliative Nurse Association

Nursing care, curricular guidelines, policy, credentialing and research information related to this specialty practice area.

<https://advancingexpertcare.org/HPNA/Default.aspx>

### National Association of Complementary and Alternative Medicine (NACAM)

Association that serves health, wellness, and beauty professionals by providing practice support, marketing materials, state licensing and insurance requirements for various disciplines.

<https://nacams.org/>

### Gerontological Society of

## America

From policy to practice –Current Issue: An interdisciplinary look at OTC analgesics and implications for patient care

<https://www.geron.org/publications/from-policy-to-practice>

## Suggested Readings

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