

---

# PALLIATIVE CARE: AN INTRODUCTION

Course # 2013  
3 Contact Hours

Author: Angeline Bushy, PhD, RN, FAAN

Material Valid Through May 2022

---

Copyright © 2019  
National Center of Continuing Education, Inc.  
All rights reserved  
Published by the  
National Center of Continuing Education, Inc.,  
Lakeway, Texas.  
Printed in the United States of America.



Enhanced Learning & Skills

**No Exams,  
Just Learning!**

Testing Mandatory For Electrologists,  
Florida & Ohio Only

---

## A NATIONAL EPIDEMIC

---

WE ALL KNOW . . .

. . . that U.S. Copyright Law grants to the copyright owner the exclusive right to duplicate copyrighted, printed and recorded materials. Piracy involves the illegal duplication of copyrighted materials.

YOU MAY NOT KNOW . . .

. . . that every time you use or make an illegal copy of any printed material in any form or by any method you may be liable for further litigation.

. . . that your institution's duplication or processing equipment may also be confiscated and destroyed if involved in illegal duplication.

. . . that the penalty for criminal violation is up to five years in prison and/or a \$250,000 fine under a tough new law. (Title 17, U.S. Code, Section 506, and Title 18, U.S. Code Section 2319).

. . . that civil or criminal litigation may be costly and embarrassing to any organization or individual. We request you contact us immediately regarding illegal duplication of these copyrighted, printed materials. The National Center of Continuing Education will pay a substantial reward for information leading to the conviction of any individual or institution making any unauthorized duplication of material copyrighted by J.R. Ivanoff or The National Center of Continuing Education, Inc.

# Table of Contents

Palliative Care: An Introduction .....	3
Disclosures .....	3
Description .....	3
Criteria for Successful Completion.....	3
Accreditation.....	3
Conflicts of Interest.....	3
Expiration Date .....	3
About the Author.....	3
Purpose and Goals.....	3
Learning Outcomes .....	3
Introduction.....	3
Role of Palliative Care .....	3
Complementary and Alternative Therapies (CAMs) .....	4
Planning, Implementing and Evaluating Palliative Care .....	4
Symptom Management .....	5
Assessing and Managing Pain .....	5
JCAHO Standards for Pain Management .....	6
Assessing and Providing Emotional Support.....	6
Assessing and Addressing Spiritual Needs .....	7
Advance Directives in Palliative Care .....	7
Initiate Discussion about End of Life Therapies.....	8
Embrace the End-of-Life .....	9
Useful terms for palliative care.....	9
Web Sites.....	12
AACN End-of-Life Nursing Education Consortium .....	12
Agency for Health Care Quality & Research (AHRQ) .....	12
American Pain Society.....	12
Before I Die.....	12
Caregivers.com .....	12
Compassionate Friends .....	12
Gerontological Society of America.....	12
Hospice and Palliative Nurse Association .....	12
Institute for Clinical Systems Improvement (ICSI) – Palliative Care .....	12
Medicare Rights Center .....	12
National Association of Complementary and Alternative Medicine (NACAM).....	12
National Coalition for Hospice and Palliative Care (NCHPC).....	12
National Family Caregivers Association .....	12
National Hospice and Palliative Care Organization .....	12
References .....	12

No part of this publication may be reproduced stored in a retrieval system or transmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise without the prior written permission of the publisher.

# Palliative Care: An Introduction

## Disclosures

### Description

**Author:** Angeline Bushy, RN, CNS, CHN, Ph.D

The goal of the course is to present the basic 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.

Learning Outcomes include:

- Define and characterize palliative care.
- State the role of palliative care and symptom management in end-of-life care.
- Summarize nursing interventions that are useful in managing pain in a person having a terminal condition.

### Criteria for Successful Completion

After reading the material, complete the online evaluation. If you have a Florida nursing license or an electrology 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

- American Nurses Credentialing Center's Commission on Accreditation (ANCC)
- 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 May 15, 2022.

## About the Author

**Angeline Bushy, PhD, RN, FAAN** is the Bert Fish Endowed Chair, University of Central Florida, College of Nursing. She has practiced in a variety of rural health care settings including the community, acute care settings and educational settings. She has published extensively, including textbooks, and presented various aspects of rural healthcare delivery at numerous national and international conferences.

## Purpose and Goals

This course presents an introduction to palliative care, with emphasis on emotional, psychosocial, spiritual and family issues; pain management. Complementary and alternative therapies are examined, along self-determination and collaborative decision making regarding end of life care.

## Learning Outcomes

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

1. Compare and contrast palliative care and hospice care.
2. Characterize the role of complementary therapies with palliative care.
3. Describe the importance of symptom and pain management in end of life care.
4. Define strategies to communicate effectively with client and family about death and dying.
5. Outline ways to address the emotional and spiritual concerns of the dying client.
6. Examine the importance of advanced directives in palliative care planning.

## Introduction

End-of-Life Care? Hospice Care? Palliative Care? These terms often are interchanged in the literature and in discussions among patients and health care providers alike. How do palliative interventions relate to hospice and end-of-life care? With respect 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 purpose of palliative care is to relieve or manage symptoms of a disease that cause suffering, but not expected to "cure" the disease. This continuing education program focuses on the activities of health professionals that are involved in providing palliative care. 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 client and his or her family system that establish priorities for care: the role of the health professional is to support the family system in achieving their unique goals. The term "family system" is broad and encompassing: it includes the client's significant other(s), immediate and extended family members, friends, and in some instances even the community. Each person i.e., patient/client) defines who is included in "family" and the membership will vary from person to person. In this program the terms "patient" and "client"

are used interchangeably.

For the past several decades, the health care system has provided a number of options to ease the dying experience. Medical treatment has expanded to include palliative care and hospice care. The goal of palliative care is to achieve an optimal quality of life for patients by using a holistic approach that focuses on the alleviation of pain, symptoms, and other unique needs of the patient at any time during their experience with a serious or life-threatening illness. A combination of social support, emotional support, attention to spiritual aspects of care; and, respect for the patient's culture, beliefs, and values are essential components of this approach. Although the level of palliative care intensifies at the end of life, the focus on the relief of suffering and improvement of quality of life is important throughout the course of the illness. Palliative care can be provided along with life prolonging treatment during earlier phases of a patient's illness (Griffith, 2018.)

Hospice care is an organized program for delivering palliative care to terminally ill patients that involves an interdisciplinary team of specially trained health professionals and volunteers. Hospice care is delivered to dying patients in inpatient units, nursing homes, or, often, in their own homes. In addition to providing palliative care and personal support to individuals at the end of their lives, hospice provides support to the family while their loved one is dying as well as during the bereavement period. In 1982, Medicare began reimbursing for hospice services. To qualify for the Medicare hospice benefit, terminally ill patients must have a terminal diagnosis, a life-expectancy of 6 months or less, and be willing to forgo further treatments that are aimed towards non-palliative care of the diagnosed terminal condition. Patients who live longer than six months can be "recertified" if their situation still meets the criteria for the hospice benefit. Medicare (2018) allows patients to continue with chemotherapy and radiation as these treatments may reduce pain (by reducing size of tumor) and will be allowed. Palliative care is any intervention that is administered to a patient that can reduce suffering and promote comfort.

## Role of Palliative Care

Palliative care is comprehensive in nature, provided by an interdisciplinary team to patients with life-threatening, advanced illness or decline. The care is focused on the patient and his or her family to alleviate suffering and promoting quality of life. Major concerns are pain and symptom management, information sharing, advanced care planning, psychosocial and spiritual support, and coordination of care.

The Center to Advance Palliative Care defines palliative care as “specialized medical care for people living with a serious illness. This type of care is focused on relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a specially-trained team of doctors, nurses and other specialists who work together with a patient’s other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.” (<https://getpalliativecare.org/>, February 18, 2019).

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), and multiple sclerosis (MS). Many residents in long-term care facilities have these conditions; therefore, should be assessed for palliative care (AHRQ, 2018).

Health professionals in general, and direct caregivers in particular, are in an ideal position to assist, share alternative perspectives to a person in their care, and enable their patient to be open about feelings and explore them further. Opportunities for meaningful interactions can be especially evident when administering personal care to the client in his or her home. Understanding and openness 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.

## Complementary and Alternative Therapies (CAMs)

Two commonly used terms are associated with palliative interventions are complementary therapies and alternative therapies. The phrases complementary therapy and alternative therapy are often used interchangeably and sometimes combined, i.e., complementary and alternative therapies (CAMs). Even though there is a distinction between complementary versus alternative therapies, in this program, the general phrase CAM is used.

According to Cancer Research UK (<https://www.cancerresearchuk.org/about-cancer/cancer-in-general/treatment/complementary-alternative-therapies/about/difference-between-therapies>, 2019) a *complementary therapy* is used in conjunction with the conventional medical treatment which may relieve symptoms, more effectively cope with the disease and the treatment and enhance one’s quality

of life. Use of these interventions generally are discussed and approved by the patient’s physician(s). In many instances, there has been research focusing on a complementary therapy to support the effectiveness in symptom management. Research continues on the benefits of the use of complementary therapies in symptom management. The effect of such therapies varies among individuals; as well as by one individual as the disease progresses. Examples of commonly used complementary therapies include:

- aromatherapy
- acupuncture
- herbal medicine
- massage therapy
- music therapy
- art therapy
- visualization
- yoga
- animal-assisted therapies
- nutrition augmentation to relieve or manage symptoms such as nausea, constipation, or insomnia.

*Alternative therapies* are used instead of conventional medical treatment. For instance, all conventional cancer treatments (e.g., chemotherapy, radiotherapy) must be rigorously researched and approved by the US Food and Drug Administration (FDA). Most alternative therapies do not have this level of scientific evidence to support or refute their effects. In fact, some alternative therapy may not have any effect while others could even be associated with harmful side effects. (<https://www.cancerresearchuk.org/about-cancer/cancer-in-general/treatment/complementary-alternative-therapies/about/difference-between-therapies>, 2019). Examples of alternative therapies which sound promising but claims have not been supported of scientific evidence include:

- Amygdalin
- vegan diets
- shark cartilage
- Gerson therapy
- Chelation therapy

Various reasons are reported for using CAM therapies, including:

- help one to generally “feel better”,
- reduce or better manage symptoms and side effects of medications and treatments
- help a client to feel more in control of one’s disease management
- natural noninvasive healing therapies are preferred over more aggressive treatment modalities
- touch, communicating and dedicated time by caregivers promote patient comfort and can enhance the human immune system
- reinforce a positive mind set in the client and family

## Planning, Implementing and Evaluating Palliative Care

The palliative care plan always is centered on the patient’s and family’s treatment goals. Discussion of symptoms and medical options with caregivers clarifies these goals and treatment approaches. In other words, palliative care is holistic and centered on the person (patient/client) (Dobrina et al., 2018; Lehman, et al, 2018). A predominate goal with palliative care is alleviating symptoms and enhancing quality of life. This may involve use of medications and other medical interventions in conjunction with CAMs. Evaluation of the interventions and the impact on the patient’s and family’s goals is ongoing. In turn, appropriate modifications in the treatment plan are discussed with the patient (family) and implemented accordingly.

Palliative care and symptom management are the essence of care for a person who is diagnosed with a chronic disease as well end stage disease symptoms. Palliative care and CAMs are focused on promoting quality of life, relief of pain and suffering, and supporting a peaceful death. These intervention encompass the active involvement of individuals who have been diagnosed with a chronic or debilitating disease that is not responsive to curative treatment interventions (Dahlin et al., 2018; Kadival et al, 2018).

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

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 with different diagnoses, affected body systems, progression of the end stage disease, and impact of these factors on the individual person. 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 different diseases (Karbasi 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, along with assisting with or providing routine activities of daily living during care, special therapies may be ordered by the physician to relieve or manage symptoms. For instance, nutritional, physical, occupational, or speech therapy may be ordered for persons with a chronic disease (i.e., COPD, Cancer, End-stage renal disease) or debilitating condition (i.e., post-stroke, post-trauma) to maintain a certain quality of life given the end stages of the disease process. 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 useful in palliative care and symptom management, such as a hospital bed with special features; oxygen, intravenous, and enterostomy therapies; wheelchair, walker, personal hygiene 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 for caregivers.

## Symptom Management

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 in the client. Follow up evaluation is critical to assess whether or not an intervention is achieving the predetermined goals (DiGiulio et al, 2018).

Symptoms encountered in palliative care that cause an intense degree of discomfort include nausea, vomiting, anorexia, pain, skin breakdown and decubitus ulcers, urinary and bowel irregularities, and respiratory problems. In some cases CAMs may help to manage and perhaps alleviate symptoms. If these cannot be managed at home, short-term inpatient care may be provided for symptom control, respite care, or terminal care (when death is imminent).

## Assessing and Managing Pain

Pain assessment, management and evaluation are important components of palliative care. In recent years major contributions have been discussed in the 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; and, sometimes even including certain family members. Adequate availability and doses of analgesics, including narcotics; around-the-clock scheduling; and the use of co-analgesics and other non-drug interventions (i.e., CAMs) have made the control of pain a more attainable goal. (Chi, et al, 2018) 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.

Analgesia includes not only drug therapy, but also non-pharmacological (CAMs) interventions such as imagery, massage, therapeutic touch, music therapy, animal assistive therapy or meditation. The goal of therapy is to keep the client comfortable, (as defined by the client) without overly impairing mental and cognitive functions that hinder participation in the activities of daily life given the particulars of disease progression. For example, activities of daily living in the early stages of the disease might include self-care and outside socialization activities. However, in the late stages of a disease, activities of daily living may become very restricted associated with severe pain (and, being bed ridden); but the patient desires to communicate coherently with family members.

Many clients and/or family members can assess and then communicate pain levels compared to the baseline tolerance level. However, some patients are stoically reluctant to admit having pain as this may be interpreted as appearing “weak”. In other instances the individual may not be able to verbally communicate discomfort such as in the end stages of life, with Alzheimer’s disease, dementia, post stroke cognitive and communication sequela and among young children. Signs of pain might include the following behaviors:

- Increased respirations
- Increase or decrease in systolic blood pressure and/or pulse from baseline
- Blinking rapidly or tightly closed eyes
- Rigid body posture or grasping a particular body part (e.g., abdomen)
- Increased restlessness, rocking, fidgeting, pacing
- Becoming aggressive, angry, belligerence or resisting care giving efforts
- Withdrawing
- Crying, moaning, calling out, sighing, attempting to speak and ask for help
- Increased confusion, disorientation and other behavior changes

Palliative care in hospice generally includes the use of opioids to control pain. Pharmacologically, these medications act by attaching to “opioid receptors” in the brain and there by block pain receptors. The most commonly prescribed opioids include

- Morphine
- Oxycodone
- Methadone
- Hydromorphone
- Fentanyl
- Codiene

The recommended hospice pain medication protocol requires the hospice team to frequently assess:

- The need to initiate and control opioids to control pain and assess the degree to which CAMs are appropriate and effective
- The selection, dosage, duration, follow-up and discontinuation of pain medication
- The level of effectiveness and patient’s comfort level in managing the pain
- The benefits versus the risk/harms of opioid use given the patient’s condition and prognoses
- That opioids are securely stored (in the home) and not misused by others in the home.

Fears of developing an addiction is frequently a concern to clients and families as well as health care professionals. Thus, teaching about pain management and facilitating the expression of beliefs about the use of medications are critical interventions if these medications are to be used effectively in palliative care and symptom management.

Use of opioids at the end of life and in hospice for pain management is important when developing the palliative care plan. While the dangers of opioid addiction are a national public health concern, this is not a priority concern at the end of life. Individuals admitted to hospice care have been diagnosed with six months or less to live. Consequently, developing an addiction is not a concern; but rather, the priority goal should be using the most effective intervention for pain management (Crossroads Hospice and Palliative care, 2019, <https://www.crossroadshospice.com/hospice-palliative-care-blog/2017/sep-tember/07/all-you-need-to-know-about-pain-management-in-hospice/>).

Measures of client comfort and function should be visible to caregivers as well as members of the family on a documentation record specifically designated for rating pain, such as a bedside flow sheet or large visible white board in the room. This information can provide a current assessment of the success of the pain control regimen. Visible documentation will 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. The American Pain Society suggests that pain rating be treated as the fifth vital sign (in addition to blood pressure, pulse, respiration,

and temperature). (American Pain Society, 2019, <http://americanpainsociety.org/>)

One strategy to objectively assess level of pain is use of a pain scale. There are numerous scales that can be used to assess pain. (Jacques, 2018, 10 Common types of pain scales, <https://www.verywellhealth.com/pain-scales-assessment-tools-4020329>). In particular, the FLACC Behavioral Scale for Assessing Pain (Face, Legs, Activity, Crying, Consolably) which was originally developed to help health professionals assess the level of pain in young children, is used to assess pain in those unable to communicate.

The FLACC is based on observations, with 0 to 2 points assigned for each of the five areas

- 0 = relaxed and comfortable
- 1-3 = mild discomfort
- 4-6 = moderate pain
- 7-10 = severe discomfort/pain

The World Health Organization (WHO) devised another simple, widely used Pain Ladder approach to pharmacotherapy for cancer pain. The five essential concepts in the WHO model approach for drug therapy of pain include the following protocol.

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

The three-step WHO Pain Ladder moves

from nonopioids, to mild opioids, then strong opioids, and in extreme cases, surgical intervention of nerves for pain relief. This approach incorporates the concept of an analgesic ladder, a rational, stepwise approach to pain management. To maintain freedom from pain, drugs should be given "by the clock", that is every 3-6 hours, rather than "on demand" This three-step approach of administering the right drug in the right dose at the right time is inexpensive and 80-90% effective in cancer patients.

(<http://www.who.int/cancer/palliative/painladder/en/>)

## JCAHO Standards for Pain Management

The Standards were developed by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) as guidance on pain management for JCAHO-accredited organizations and interested health care professionals. 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 is available at [http://www.jointcommission.org/topics/pain\\_management.aspx](http://www.jointcommission.org/topics/pain_management.aspx).

**Table 1: FLACC Behavioral Pain Scale**

Scoring			
Categories	0	1	2
Face	No particular expression or smile	Occasional grimace or frown, withdrawn, disinterested	Frequent to constant frown, quivering chin, clenched jaw
Legs	Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drawn up
Activity	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arched, rigid, or jerking
Cry	No cry (awake or asleep)	Moans or whimpers; occasional complaint	Crying steadily, screams or sobs, frequent complaints
Consolability	Content, relaxed	Reassured by occasional touching, hugging, or being talked to; distractable	Difficult to console or comfort

**Note:** each of the five categories Face(F), Legs (L), Activity (A), Cry (C), and Consolability (C) is scored from 0-2, which results in a total score between 0 and 10. From Merkel, Voepel-Lewis, Shayevitz, & Malviya (1977). The FLACC: A behavioral scale for scoring postoperative pain in young children. *Pediatric Nursing*, 23 (3) 293-297.

## Assessing and Providing Emotional Support

Health professionals providing palliative care must be sensitive to the reality that depression, anxiety, and sleep disorders may be present and may cause physical or emotional symptoms in the client as well as family members. Furthermore, unique psychosocial issues often accompany a 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 the various members of the family. Coping skills to deal with the chronic disease and impending death of the loved one also may be limited, or even dysfunctional, in some families. Even family systems that have effective coping abilities may find relationships strained at some time during a terminal illness of one of its members (Forbat et al, 2018; Rawlings et al, 2018; Smith et al, 2018).

Obviously, one of the most critical components of providing emotional support with 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 on the part of the client. Most people at the end of life want to talk about the process of their own death with loved ones. Sometimes the dying person needs to be granted permission to discuss his or her concerns and feelings about this major life event. Often, family members feel extreme discomfort with the topic, and are unable to participate in discussions with loved ones about death and dying. In turn, this deters the dying person from initiating the subject or express personal wishes regarding end of life care. In these situations, a health professional can facilitate discussion among the family system to talk about end-of-life wishes, dying and death. Many times, actually saying the words “death” and “dying” provides an opening for dialogue to begin on the topic. If the caregiver is comfortable with those words that, in and of itself, can help others to feel more comfortable talking about the highly sensitive topics of death, loss and grieving.

For example, Lucinda, a 72 years old female, had end stage cardiac disease and was having trouble making a decision about continuing to live at home. Lucinda 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 Lucinda 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.” The home health nurse informed Lucinda that she was capable of making her own decision. To help reduce the family’s anxiety, Lucinda agreed to carry a cell phone with automated dialing for quick access to her family and doctor. This strategy reassured the family, and yet allowed for Lucinda to live at home even with the seriousness of her illness. At the end, upon making a routine home visit, the home health nurse found Lucinda deceased in her own bed. In essence, the care plan for Lucinda focused on assisting her to live and die in the manner she desired.

## Assessing and Addressing Spiritual Needs

Often when health professionals consider spiritual care, or the spiritual needs of clients, they think of a specific religious ritual (e.g. sacraments of penance, communion or sacrament of the sick) or contacting a particular religious leader (e.g. rabbi, priest, or minister). However, spiritual needs should be more broadly considered than a person’s relationship to God or another higher power, or adherence to the tenants of a particular religion, or another higher power (Webb et al, 2018). The spiritual needs of humans include one’s perspective regarding:

1. the need for meaning and purpose of life
2. the need for love, relatedness and connectedness
3. the need for forgiveness

Throughout history humans have searched for the meaning of life. Likewise, this search has been the primary motivation for life’s richest and most satisfying experiences. For many, ultimate hope and meaning comes from a relationship with God; or, however they conceptualize a higher spiritual power in their life. This spiritual connection is especially important for a person when confronting life’s end. Reliance on people and worldly achievements is minimized, and the focus is on an unknown future. The dying person may turn increasingly toward a higher power. Those who have a relationship with God or another higher power are more likely to contemplate that future with hope and a greater sense of peace at the end of life.

The need for love, connectedness and a relationship with others is another profound spiritual need. The dying person is no longer in a position to earn love from other people or try to meet the conditions required to obtain or maintain their love. Guilt is one of the greatest burdens in life associated with a perceived sense of failure of living up to another person’s

or God’s expectations. The dying person needs time to “settle” differences and to receive forgiveness from others in order to die peacefully.

Dr. Ira Byock, author, palliative care advocate, and director of the Institute for Human Caring of Providence Health and Services, (The Best Care Possible, 2012) suggests the dying patient should respond in writing the following items; then, share that letter with appropriate family members and friends:

- Please forgive me.
- I forgive you.
- Thank you.
- I love you.
- Goodbye.

Is it appropriate for a nurse 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 routine with stereotypical responses. Each individual is unique, and so are his or her beliefs and needs concerning spirituality.

Health care providers, in general, should first be aware of their personal religious and spiritual perspectives in order to therapeutically address the spiritual needs of a client. In particular a nurse must be confident about personal values and beliefs which requires facing and resolving personal views regarding death and dying. Essentially, this process entails “being” as opposed to “doing”. Therapeutic use of self involves listening, empathy, humility, and commitment. The nurse must be willing to continue in the relationship as long as the other individual needs spiritual support. The nurse may experience corresponding pain and grief when becoming involved with clients this extensively. However, knowing that one has helped the dying person through one of the most difficult and stressful times can be very rewarding for the care giver.

## Advance Directives in Palliative Care

With respect to palliative care, the nurse must recognize 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 advance 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.

The Institute for Clinical Systems Improvement (ICSI, 2013) published the following recommendations for palliative care.

- 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 generally is 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.

## Initiate Discussion about End of Life Therapies

Health care professionals 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? 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. Use of a mnemonic can help providers to better understand the emotions, questions and problems that may arise with patients and families at the end of life.

The mnemonic *ABCDE* is a useful prompt to initiate a conversation with patients and families.

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/rela-*

*ship:*

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. For example state:

- "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, jargon 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 (Wen et al, 2018). Recognize that denial, blame, intellectualization, disbelief, and acceptance may be present to varying degrees and time frames. Watch for signs of depression and suicidal ideation 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. For example state:

- "I probably was raised different 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. For example state:

- “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, many of which remain unstated and may even be in conflict with those of the care giver (Cresp et al, 2018)

## Embrace the End-of-Life

Creating an atmosphere and purposeful preparation can assist the patient and family through an oftentimes, difficult process. It takes great strength and courage to face death and to begin to move through it to the other side. Courage is also necessary for survivors to put aside personal anxieties in order to assist a loved one at the end of life (Bar-Sela, et al, 2018; Byock, 2012; Jang et al, 2018).

Experiences gained while attending to the dying indicate that listening and respecting the dying person’s concerns are essential for end-of-life care. Pain management and physical concerns must be first addressed. Then, address concerns of the spirit however this may be expressed. Begin by finding out about the patient’s religious and cultural background. Nearly everyone has religious and/or cultural images and beliefs that affect how they live and how they view death. Build upon common religious rites or teachings that have meaning for the patient in order to create a personalized touch. (Scriptures, sacred texts, poetry, and prayers can be used as starting points.)

Cultural awareness and identification are essential. Assess the patients through his or her eyes along with the eyes of the family system. First and foremost, develop an understanding of one’s own perspective. Knowing or thinking personal feelings and attitudes will influence care that is provided in another’s end-of-life experience. Family structure, belief systems, roles/decision making, how emotions are handled, response to illness and attitudes toward pain and procedures and communication styles may differ among cultural groups.

The dying person must be treated with absolute respect. If a person is conscious and able to talk, listen and take cues from him. Every effort should be made to respond to the desires of the

dying person, however seemingly illogical or puzzling. Reassure the patient and do whatever necessary to address the person’s requests. Do not diminish the patient’s reality. Instead, accept that the patient could be experiencing things we may be unaware of. To those who are unconscious or in a coma speak “as if he is able to hear and understand.” In addition to helping patients let go of this life, rituals can help them put things in order and resolve issues between family and friends. Sometimes the unfinished business is with God or another higher power. By setting the stage, the releasing of emotions such as anger, fear, sorrow, guilt, and burdens can occur. Rituals can also promote comfort and peace within. With the deepest respect and attentiveness, we can learn how to nurture peace and spiritual healing in those who are making this final transition.

Working with the terminally ill is emotionally demanding especially when confronting death on a daily bases. What can be done to effectively cope with this stress to prevent professional “burnout”? (Meziane et al, 2018)

- Get to know yourself. Identify your emotional strengths and limitations.
- Develop your own philosophy of life and death. Develop insights about what you believe as this can help to decrease anxiety and frustrations.
- Build a support system both at work and at home. Find people who will listen and care about you and the grief you experience when caring for patients at the end of life. Communicate feelings and frustrations, but do NOT dwell on them. A hobby, exercise, rest, mediation and pets can be useful coping skills to help manage anxiety and stress.
- Develop a sense of humor and use it. Learn to laugh at yourself and at life in appropriate ways. When working with terminally ill people on a daily basis it is easy to get morbid and cynical about life and death.
- Education can be of great assistance personally and professionally. Learn about the needs of the dying and how to meet those needs. Personal empowerment involves understanding how to intervene and assist others at the end of life.

There are no easy answers or ‘magic bullets’. Even with this information, death remains difficult for us. However, providing care and comfort to an individual at the end of life can be both challenging and rewarding for the health professional.

In Dr. Byock’s New York Times editorial “*Dying Shouldn’t Be So Brutal*” (<https://opinionator.blogs.nytimes.com/2015/01/31/dying-shouldnt-be-so-brutal/>) the Academy of Hospice and Palliative Medicine Lifetime Achievement

Award winner shares his views and expertise with the American public. These excerpts from that editorial encapsulate the fundamentals of palliative care.

“modern medicine has yet to make even one person immortal. Therefore, at some point, more treatment does not equal better care.”

“People who are approaching the end of life deserve the security of confident, skillful attention to their physical comfort, emotional well-being and sense of personal dignity. Their families deserve respect, communication and support. Exemplary health systems and healthy communities deliver all of this today.”

“Most people want to drift gently from life, optimally at home, surrounded by people they love.”

“Over the past two decades the fields of geriatrics, hospice and palliative medicine have demonstrated that much better care is both feasible and affordable. Successful approaches share core attributes: meticulous attention to alleviating people’s symptoms and maximizing their independence, continuing communication and coordination of services, crisis prevention and early crisis management, and decision making rooted in patients’ and families’ values, preferences and priorities. Together these steps reliably improve sick people’s quality of life, modestly extend survival and save money.”

## Useful terms for palliative care

These terms appear in the National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. <https://www.nationalcoalitionhpc.org/ncp> [https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines\\_4thED\\_web\\_FINAL.pdf](https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf)

### Acculturation:

“...the process of cultural and psychological change that results following meeting between cultures.”

### Activities of daily living (ADLs)

“...are activities related to personal care.

They include bathing or showering, dressing, getting in and out of bed or a chair, walking, using the toilet, and eating.”

**Advanced practice providers:**

Defined in the NCP Guidelines as physician assistants and advanced practice registered nurses utilized to expand the capacity of palliative care interdisciplinary teams to deliver complex care and provide direct care.

**Advance care planning documents:**

“...allow individuals to share their treatment preferences in the event they can no longer speak for themselves.” There are two kinds: legal documents and medical orders (eg, legal: living wills, health care surrogate; medical: do not resuscitate (DNR) orders, physician orders for life-sustaining treatment (POLST)).

**Anticipatory grief:**

“...a complex concept that encompasses grief in anticipation of the future loss of a loved one, in addition to previously experienced and current losses as a result of the terminal illness.”

**Autonomy:**

“The principle of respect for autonomy is usually associated with allowing or enabling patients to make their own decisions about which health care interventions they will or will not receive.”

**Beneficence:**

“The ethical principle of beneficence requires healthcare professionals to treat their patients in a way that provides maximum benefit to that patient.”

**Bereavement:**

“The process of grieving and letting go of a loved one who has died.”

**Capacity:**

See “Decision-making capacity.”

**Care coordination:**

“Care coordination is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient’s care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care.”

**Care plan:**

In palliative care, the interdisciplinary team develops the care plan, with input from all health and social support providers. The care plan is based on the patient’s goals of care, as well as information gathered via the comprehensive assessments. The services and support needed to achieve those goals and reduce suffering are described, including plans to monitor

and adjust the plan based on subsequent patient and family assessments.

**Care transitions:**

“The term care transition describes a continuous process in which a patient’s care shifts from being provided in one setting of care to another, such as from a hospital to a patient’s home or to a skilled nursing facility and sometimes back to the hospital.” In addition, care transitions occur when patients change care providers.

**Caregiver assessment:**

“Caregiver assessment is a systematic process of gathering information about a caregiving situation to identify the specific problems, needs, strengths, and resources of the family caregiver, as well as the caregiver’s ability to contribute to the needs of the care recipient.”

**Cognitive impairment:**

“Cognitive impairment is when a person has trouble remembering, learning new things, concentrating, or making decisions that affect their everyday life. Cognitive impairment ranges from mild to severe. With mild impairment, people may begin to notice changes in cognitive functions, but still be able to do their everyday activities. Severe levels of impairment can lead to losing the ability to understand the meaning or importance of something and the ability to talk or write, resulting in the inability to live independently.”

**Communication:**

In palliative care, “promoting and facilitating open communication to foster patient- and family-centered shared decision-making, and advance care planning is essential. Ethnic and cultural differences should be acknowledged. Family members’ decision-making strategies around options of care, location, and preferences should take into account cultural, ethnic, and religious preferences. The earlier these discussions can occur, the better, so when there are unexpected changes in a patient’s condition, discussions have already happened, and decisions have been made.”

**Comprehensive assessment:**

“Rather than gathering information exclusively from the patient (or caregivers) and medical records, palliative evaluation utilizes a broad range of sources, each contributing to the final assessment. In an interdisciplinary manner, the physician collaborates with nursing staff, chaplains, social workers, therapists, and nutritionists to perform discipline-specific evaluative tasks, together developing the comprehensive palliative assessment. Tasks that are best shared with expert nonphysician team members may include evaluation of existential and spiritual domains, economic needs, and care coordination; however, specific distribution will vary depending on local expertise.”

**Continuous quality improvement (CQI):**

uses an “‘iterative approach that aims to reduce and eventually eliminate ‘unexplained clinical variation.’ Reducing such variation addresses the root of many of health care’s inefficiencies, excess costs, and poor outcomes. CQI calls for a cultural shift that relies on clinicians constantly asking themselves, ‘How could this process be better?’ and ‘How can I impact this change?’ The underpinnings of this approach view each clinician as an informed agent who can identify bad processes and implement changes. It views medical errors and inefficiencies as results, not of bad people, but of suboptimal processes of care. CQI also recognizes that heterogeneity in patient characteristics, values, and clinical settings dictates that prudent decision-making formulated to reduce unnecessary clinical variation does not mean that 100% of care may meet a quality measure.”

**Cultural humility:**

“In a multicultural world where power imbalances exist, cultural humility is a process of openness, self-awareness, being egoless, and incorporating self-reflection and critique after willingly interacting with diverse individuals. The results of achieving cultural humility are mutual empowerment, respect, partnerships, optimal care, and lifelong learning.”

**Decision-making capacity:**

“Medical decision-making capacity refers to the time-sensitive determination of a patient’s ability to make a specific clinical choice.” 17 Thoughtful assessment of capacity is essential for providing care that preserves and respects a patient’s autonomy, while meeting the ethical and legal standards of informed consent.

**Developmentally appropriate:**

Providers of palliative care seek to provide developmentally appropriate care to all people living with a serious illness. Such care “incorporates advanced decision making based on young adult cognitive abilities, acknowledges and treats the high symptom burden, promotes this time of psychological and spiritual growth, and ultimately, empowers and honors this special time of life.”

**Family:**

The patient defines who constitutes their family and “determine how they will participate in care and decision-making.”

**Family caregiver:**

“A family caregiver is someone who is responsible for attending to the daily needs of another person. Family caregivers are responsible for the physical, emotional and often financial support of another person who is unable to care for him/herself due to illness, injury or disability. The care recipient may be a family member, life partner or friend.”

**Grief:**

“The emotional, cognitive, functional and behavioral responses to the death. Also, grief is often used more broadly to refer to the response to other kinds of loss; people grieve the loss of their youth, of opportunities, and of functional abilities.”

**Health care surrogate (health care proxy, health care agent):**

A health care surrogate is someone appointed to make health care decisions when the patient is unable to make or communicate decisions. The surrogate can be appointed by the patient via an advance directive, or serve as a court-appointed guardian. If the health care providers are unable to locate a decision-maker, a decision-maker may be appointed in accordance with state laws.

**Hospice:**

“Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient’s needs and wishes. Support is provided to the patient’s loved ones as well.” “Hospice focuses on caring, not curing and in most cases care is provided in the patient’s home. Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients of any age, religion, race, or illness. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations.”

**Interdisciplinary team:**

“The interdisciplinary model is based on synergistic and interdependent interaction of team members who each possess particular expertise. Team members work closely together, actively communicating and sharing information. Leadership is often task-dependent, defined by each situation. Collaboration is identified as the process central to the interactions between members.”

**Long-term services and supports (LTSS):**

“...encompasses the broad range of paid and unpaid medical and personal care assistance that people may need – for several weeks, months, or years – when they experience difficulty completing self-care tasks as a result of aging, chronic illness, or disability.”

**Non-beneficial care:**

“A treatment determined on the basis of current medical knowledge and experience to hold no reasonable promise for contributing to the patient’s well-being or of achieving agreed-on goals of care.”

**Nonmaleficence:**

“Obligation not to inflict harm intentionally.”

**Palliative care:**

Palliative care focuses on expert assessment and management of pain and other symptoms, assessment and support of caregiver needs, and coordination of care. Palliative care attends to the physical, functional, psychological, practical, and spiritual consequences of a serious illness. It is a person- and family-centered approach to care, providing seriously ill people relief from the symptoms and stress of an illness. Through early integration into the care plan of seriously ill people, palliative care improves quality of life for both the patient and the family.

**Palliative care interdisciplinary team (IDT):**

Specialty palliative care interdisciplinary teams collaborate with other care providers to directly provide and coordinate care. Depending on the care needs of each patient and family, the IDT can expand to include other clinicians and community service providers. All team members are responsible to screen for unmet needs outside of their scope and access team members with expertise for full assessments.

**Palliative care specialists:**

Palliative care specialists include “physicians who are board certified in this specialty; palliative-certified nurses; and palliative care-certified social workers, pharmacists, and chaplains.”

**Primary palliative care (also known as generalist):**

“Palliative care that is delivered by health care professionals who are not palliative care specialists, such as primary care clinicians; physicians whom are disease-oriented specialists (such as oncologists and cardiologists); and nurses, social workers, pharmacists, chaplains, and others who care for this population but are not certified in palliative care.”

**Professional chaplain:**

The professional chaplain is master’s level prepared and has participated in clinical chaplaincy training. Board Certification in chaplaincy is preferred. Certified chaplains may also specialize in palliative care and have specialized certification. The chaplain is the spiritual care specialist on the interdisciplinary team, and is trained to address spiritual and religious concerns of all patients and caregivers, regardless of their spiritual or religious beliefs and practices. The chaplain is also an emotional care generalist, and interfaces closely with the social worker and other mental health providers to provide psychosocial-spiritual care as a unified domain.

**Psychological/psychiatric:**

“The psychosocial implications of disease

progression result in a range of challenges for both the patient and the caregiver. The consequences of advanced disease can comprise emotional states such as anxiety, distress and depressive episodes, fear of being a burden to others, loss of control, anger, loss of sense of dignity, uncertainty, and changes in close relationships and social roles. Adjustment disorder, anxiety disorder, depressive disorder, and the demoralization syndrome represent common disorders and phenomena among patients with advanced cancer. Moreover, uncontrollable pain and high unrelieved physical symptom burden, depression, feelings of helplessness and hopelessness, delirium, and low family support are major factors in the desire for thoughts of suicide and the desire for hastened death. Caregivers play an important and challenging role, providing emotional and social support for the patient, helping with medical needs, and meeting increasingly complex instrumental needs such as running the household and work.”

The psychiatric syndromes that may manifest for a patient and/or family member during a serious or life-threatening illness include depression, anxiety, and delirium. Patients and family members may already be diagnosed with a mental health disorder, which could include any listed in the Diagnostic and Statistical Manual of Mental Disorders (DSM-V). Psychiatric conditions can be challenging for palliative care staff to differentiate from the serious illness because symptoms may intersect with those of the medical conditions. Psychiatry can assist in these situations, as well in the use of psychotropic medications.

**Religion:**

“...involves beliefs, practices, and rituals related to the sacred. Religion may also involve beliefs about spirits, both good (angels) and bad (demons). Religion may be organized and practiced within a community, or it may be practiced alone and in private. In either case, religion originates in an established tradition that arises out of a community with common beliefs and practices.”

**Serious illness:**

Serious illness is defined as a “health condition that carries a high risk of mortality and either negatively impacts a person’s daily function or quality of life or excessively strains their caregiver.”

**Shared decision-making:**

“At its core, shared decision making is an interpersonal, interdependent process in which the health care provider and the patient relate to and influence each other as they collaborate in making decisions about the patient’s health care.” “Three essential elements must be present for shared decision making to occur. First, both the health care provider and the patient

must recognize and acknowledge that a decision is, in fact, required. Second, they must both know and understand the best available evidence concerning the risks and benefits of each option. Third, decisions must take into account both the provider's guidance and the patient's values and preferences."

#### **Spirituality:**

Spirituality is recognized as a fundamental aspect of compassionate, patient and family-centered care. "Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred."

#### **Spiritual assessment:**

"Formal spiritual assessment refers to a more extensive process of active listening to a patient's story conducted by a board-certified chaplain that summarizes the needs and resources that emerge in that process. The chaplain's summary should include a spiritual care plan with expected outcomes that is then communicated to the rest of the treatment team. Unlike history taking, the major models for spiritual assessment are not built on a set of questions that can be used in an interview.

Rather, the models are interpretive frameworks that are based on listening to the patient's story as it unfolds. Because of the complex nature of these assessments and the special clinical training necessary to engage in them, this assessment should be done only by a board-certified chaplain or an equivalently prepared spiritual care provider."

#### **Spiritual distress:**

"...a state of suffering related to the impaired ability to experience meaning in life through connectedness with self, others, world or a Superior Being. This definition contains the attributes of spiritual distress: suffering, impaired spirituality, contrary to spiritual well-being, and related to meaning in life."

#### **Spiritual screening:**

"Spiritual screening or triage is a quick determination of whether a person is experiencing a serious spiritual crisis and therefore needs an immediate referral to a board-certified chaplain. Spiritual screening helps identify which patients may benefit from an in-depth spiritual assessment. Good models of spiritual screening use a few simple questions that can be asked in the course of an overall patient and family screening. Examples of such questions include, 'Are spirituality or religion important in your life?' and 'How well are those resources working for you at this time?'"

#### **Substituted judgement:**

Substituted judgement refers to the ethical duty of guardians and surrogate decision-

makers to make an effort to understand the patient's beliefs and values prior to making decisions on the patient's behalf.

#### **Total pain:**

A holistic experience that extends beyond the physiological domain and was first introduced by Dame Cicely Saunders in the 1960s. Total pain recognizes the holistic nature of pain and the interplay of psychological and social well-being, spirituality, and culture. Symptoms rarely occur in isolation; rather, they cluster with other symptoms and are influenced by the psychological, social, and cultural characteristics of the individual.

## **Web Sites**

### **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>

### **Agency for Health Care Quality & Research (AHRQ)**

<https://www.ahrq.gov/research/findings/nhqrd/r/chartbooks/healthyliving/supportive.html>

### **American Pain Society**

<http://americanpainsociety.org/>

### **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/>

### **Caregivers.com**

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

### **Compassionate Friends**

Assists families in the positive resolution of grief following the death of a child.

<http://www.compassionatefriends.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>

### **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>

### **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/)

### **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 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/>

### **National Coalition for Hospice and Palliative Care (NCHPC)**

<https://www.nationalcoalitionhpc.org/ncp/>

### **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>

## References

- Agency for Health Care Quality & Research (AHRQ). (2018). Supportive and palliative care: National healthcare and quality disparities report. Accessed February 26, 2019. <https://www.ahrq.gov/research/findings/nhqrdr/chartbooks/healthyliving/supportive.html>
- American Pain Society (2019). Accessed February 26, 2019 <http://americanpainsociety.org>
- Bar-Sela G, Schultz MJ, Elshamy K, Rassouli M, et al. (2018) Training for awareness of one's own spirituality: A key factor in overcoming barriers to the provision of spiritual care to advanced cancer patients by doctors and nurses. *Palliative Support Care*, 6, 1-8. doi: 10.1017/S147895151800055X.
- Brooks LA, Bloomer MJ, Manias E. (2018) Culturally sensitive communication at the end-of-life in the intensive care unit: A systematic review. *Australian Critical Care*. Accessed February 26, 2019. ><https://www.sciencedirect.com/science/article/pii/S1036731418300572?via%3Dihub>
- Bybee S. (2018). Vicarious posttraumatic growth in end-of-life care: How filling gaps in knowledge can foster clinicians' growth. *Journal of Social Work End of Life Palliative Care*, 3, 1-17. doi: 10.1080/15524256.2018.1498820
- Byock, I. (2012). The best care possible: A physician's quest to transform care through the end of Life. Avery.
- Byock, I. (2015, Feb.). Dying shouldn't be so brutal: Opinion Blog. The New York Times. Accessed March 12, 2019. <https://opinionator.blogs.nytimes.com/2015/01/31/dying-shouldnt-be-so-brutal/>
- Cancer Research UK. (2019). Accessed February 26, 2019. <https://www.cancerresearchuk.org/about-cancer/cancer-in-general/treatment/complementary-alternative-therapies/about/difference-between-therapies>
- Center to Advance Palliative Care. (2019). Accessed March 12, 2019. <https://getpalliativecare.org/>.
- Centers for Medicare & Medicaid Services (2019) Key search Palliative Accessed March 13, 2019. [https://cmit.cms.gov/CMIT\\_public/ListMeasures?q=palliative](https://cmit.cms.gov/CMIT_public/ListMeasures?q=palliative)
- Chi NC, Han S, Barani E, et al. (2018) Development and preliminary evaluation of a pain management manual for hospice providers to support and educate family caregivers. *American Journal of Hospice and Palliative Care*. doi: 10.1177/1049909118804984. [Epub ahead of print]
- Cresp SJ, Lee SF, Moss C. (2018). Substitute decision makers' experiences of making decisions at end of life for older persons with dementia: A systematic review and qualitative meta-synthesis. *Dementia (London)*. doi: 10.1177/1471301218802127. [Epub ahead of print]
- Dahlin C, Coyne P. (2018). The palliative APRN leader. *Annals of Palliative Medicine*. doi: 10.21037/apm.2018.06.03. [Epub ahead of print]
- Dobrina R, Tenze M, Palese A. (2018) Transforming end-of-life care by implementing a patient-centered care model: Findings from an action research project. *Journal of Hospital Palliative Nursing*. doi: 10.1097/NJH.0000000000000468.
- Di Giulio P, Finetti S, Giunco F, et al. (2018). The impact of Nursing Homes staff education on end-of-life care in residents with advanced dementia: a quality improvement study. *Journal of Pain and Symptom Management*. Accessed February 26, 2019. [https://www.jpmsjournal.com/article/S0885-3924\(18\)30775-9/fulltext](https://www.jpmsjournal.com/article/S0885-3924(18)30775-9/fulltext)
- Forbat, L., Cert, P., Francois, K, et al. (2018). Family meeting in inpatient specialist palliative care: A mechanism to convey empathy. *Journal of Pain and Symptom Management*. Accessed February 26, 2019. [https://www.jpmsjournal.com/article/S0885-3924\(18\)30040-X/fulltext](https://www.jpmsjournal.com/article/S0885-3924(18)30040-X/fulltext)
- Griffith S. (2018). Prepared for end-of-life care: a concept analysis. *International Journal of Palliative Nursing*, 24(8), 399-410. doi: 10.12968/ijpn.2018.24.8.399.
- Institute for clinical systems improvement (ICSI). Palliative care for adults. Accessed February 26, 2019 <https://www.icsi.org/?s=palliative+care>
- Jang S., Park W., Kim H., Chang S. (2018). Exploring nurses' end-of-life care for dying patients in the ICU using focus group interviews. *Intensive Critical Care Nursing*. doi: 10.1016/j.iccn.2018.09.007.
- Jacques, E. (2018). 10 Common types of pain scales. Accessed February 26, 2019. <https://www.verywellhealth.com/pain-scales-assessment-tools-4020329>
- The Joint Commission (JCAHO). Website search terms; pain management, hospice care, palliative care. Accessed February 26, 2018. [http://www.jointcommission.org/topics/pain\\_management.aspx](http://www.jointcommission.org/topics/pain_management.aspx).
- Kadivar M, Mardani-Hamooleh M, Kouhnavard M. (2018). Concept analysis of human dignity in patient care: Rodgers' evolutionary approach. *Journal of Medical Ethics*, 11 (4). Accessed February 26, 2019.
- Karbasi C, Pacheco E, Bull C, et al. (2018). Registered nurses' provision of end-of-life care to hospitalised adults: A mixed studies review. *Nurse Education Today*, 13(71), 60-74. Accessed February 26, 2019. From <https://ac.els-cdn.com/S0260691718306002/1-s2.0-S0260691718306002-main.pdf>
- Lehman, R, Tejani, A, et al. (2015). The 10 commandments for patient centered care. *British Journal of General Practice*, 65 (639), 523-533. Last Accessed March 12, 2019. <https://bjgp.org/content/65/639/532>
- Medicare/Medicaid. (2018). Hospice and palliative care. Accessed February 26, 2019, <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/ltss-focus-areas/hospice-and-palliative-care.html>
- Medline Plus. (2018). Advance directives. Accessed February 26, 2019. <https://medlineplus.gov/advancedirectives.html>
- Merkel S, et al. The FLACC: A Behavioral Scale for Scoring Postoperative Pain in Young Children *PEDIATRIC NURSING*, May-June 1997/Vol.23/No. 3 [https://www.researchgate.net/publication/13998379\\_The\\_FLACC\\_A\\_Behavioral\\_Scale\\_for\\_Scoring\\_Postoperative\\_Pain\\_in\\_Young\\_Children](https://www.researchgate.net/publication/13998379_The_FLACC_A_Behavioral_Scale_for_Scoring_Postoperative_Pain_in_Young_Children)
- Meziane D, Ramirez-Garcia M, Fortin M. (2018). A reflective practice intervention to act on the moral distress of nurses providing end-of-life care on acute care units. *International Journal of Palliative Nursing*, 24(9), 444-451. doi: 10.12968/ijpn.2018.24.9.444.
- National Coalition for Hospice and Palliative Care (NCHPC). (2018). National consensus project clinical practice guidelines for quality palliative care guidelines, 4th Ed.. Last Accessed March 13, 2019. <https://www.nationalcoalitionhpc.org/ncp/>, <https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC->

- Rawlings D, Tieman J, Miller-Lewis L, Swetenham K. (2018). What role do death Doulas play in end-of-life care? A systematic review. *Health and Social Care in the Community*, 1-13. doi.org/10.1111/hsc.12660
- Smith D, Hall D, Parke G, Lane R, Gray A. (2018). No place like home: A case study of a patient discharged from an Intensive Care Unit for end of lifecare at home. *Journal of Intensive Care Society*, 19(3), 259-263. doi: 10.1177/1751143717751324.
- Webb WA, Mitchell T, Snelling P, Nyatanga B. (2018). The spiritual concerns of people experiencing homelessness at the end of life. *International Journal of Palliative Nursing*, 24(9), 428-435. doi: 10.12968/ijpn.2018.24.9.428.
- Wen F, Chen J, Chou W, et al. (2018). Family caregivers' subjective caregiving burden, quality of life, and depressive symptoms are associated with terminally ill cancer patients' distinct patterns of conjoint symptom distress and functional impairment in their last 6 months of life. *Journal of Pain and Symptom Management*, 17(6), 418-428. doi.org/10.1016/S0885-3924(99)00014-7
- World Health Organization (WHO). (2019). Palliative Care. Accessed February 26, 2019. <http://www.who.int/cancer/palliative/painladder/en/>