

palliative people
get medicine diagnosis return died live
patients families patient health help question 80
quality chronic regular serious
need care

CALIFORNIA
ASSOCIATION OF
HEALTH FACILITIES



2014 Quality Improvement Subcommittee

TABLE OF CONTENTS

Section One

Introduction to Palliative Care for Skilled Nursing Facilities

Section Two

Palliative Care “Fast Fact Sheet”

Section Three

Palliative Care Workgroup: Clinician Guidelines

Section Four

Introduction to Palliative Care for Residents and Families

Section Five

Resources

Section One

Introduction to Palliative Care for Skilled Nursing Facilities

INTRODUCTION TO **PALLIATIVE CARE** FOR SKILLED NURSING FACILITIES

CAHF®



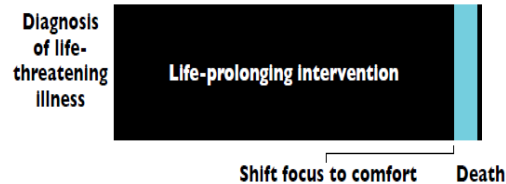
What is Palliative Medicine?

- ➔ An interdisciplinary medical specialty that focuses on preventing and relieving suffering and supporting the best possible quality of life for patients and families facing serious illness.
 - It is not just for residents at the end of their life.
 - Hospice care is a form of palliative care, but not all palliative care is hospice care.

2

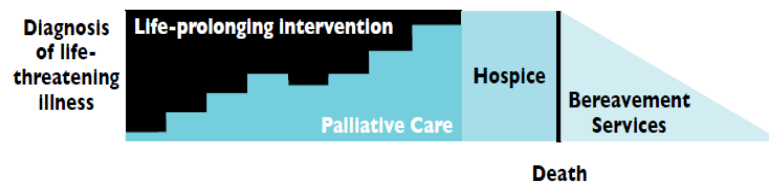
Traditional Care vs. Palliative Care

Figure 1. Traditional Care Model



Source: *Palliative Care Best Practices: A Guide for Long-Term Care and Hospice*
CIVHC | Center for Improving Value in Health Care

Figure 2. Integrated Care Model



Principles of Palliative Care in Long Term Care

- It is beneficial to patients with multi-system failure and progressive loss of function.
- It is individualized based on physical, cultural, mental and spiritual needs.
- Goals of care are determined by the patient, family and/or surrogate.
- Goals and interventions change as the disease and needs of the patient progress.

Who is a Candidate for Palliative Care Assessment?

(Multiple criteria need not be present)

- Eligible for hospice, but not psychologically ready.
- Life expectancy of 12 to 24 months or progressive/serious chronic illness.
- Frequent admissions or ER visits – repeated admission for same condition(s) within several months.
- Complex symptoms – admission for difficult symptom management/ psychological needs.
- Complex care requirement – functional dependence or complex home support needed.
- Need assistance in advance care planning and defining goals of care.
- Limited social support – family stress, chronic mental illness, lack of caregivers, or conflict within family.

Palliative Medicine Concept of Total Pain

The focus is on the individual needs of each resident as it relates to:

- Physical pain
- Social pain
- Psychological pain
- Spiritual pain

A COMBINATION OF ANY OR ALL OF THESE
IS ASSOCIATED WITH POOR QUALITY OF LIFE.

Palliative Care – Core Skills – System Control

Symptom control is essential to successful palliative care interventions. These symptoms include but are not limited to:

- A. Pain
- B. Dyspnea
- C. Bowel Difficulty
- D. Nausea/Vomiting
- E. Fatigue

Report any changes in these areas to the physician and to the palliative care team.

Palliative Medicine – Core Skills Psychological Assessment

- Provides information to increase the value of the staff/patient/family relationship.
- Provides information related to family stressors, spiritual ambiguity and how the patient is progressing through the grief process.
- Helps in identifying feelings related to the loss of independence, financial issues and unresolved personal relationships.

Palliative Medicine – Core Skills – Advance Care Planning

- Provides assistance and guidance to the patient and family in developing Advance Care Planning.
- This includes, but is NOT limited to advance healthcare directives, POLST, goals of care, coordination of care with caregivers and medical team.
- These plans are individualized and person-centered.

Palliative Medicine – Core Skills – Communication

It is essential that Palliative Care staff are provided with the tools to effectively communicate their services to the resident and family members.

COMMUNICATION RESOURCES:

The Conversation Project
www.theconversationproject.org

The Coalition for Compassionate Care
<http://coalitionccc.org/nursing-homes.php>
<http://coalitionccc.org/tools-resources/decision-guides>

Palliative Medicine – Core Skills – Communication

How can we facilitate that good communication?

- Provide all necessary records and information.
- Provide a private space for the family/resident and Palliative staff to meet.
- Avoid interruptions.
- Provide refreshments, tissues, adequate seating prior to the meeting.
- Be prepared to respond to family concerns or questions in a supportive manner.
- Become familiar with the Palliative Care goals and priorities for the patient.

Benefits to Patients and Families

- “Total Pain” control
- Reduced hospitalizations
- Reduced ED visits
- Improved communication
- Goals of care discussion
- Improved quality of life
- Improved satisfaction with the health system

Benefits to Skilled Nursing Facilities

- Part B benefit; does not interfere with Part A billing.
- Assistance with pain and symptom management to maximize length of stay.
- Increased support and comfort = quality of life.
- Resource for dealing with emotional families and patients.
- Focus on reduction of hospital admissions and readmissions.
- Provide resources to help coordinate care for patients who are being discharged home or for those who elect hospice.
- Assistance in identifying and treating residents with potential or actual pain management problems.

Resources for Palliative Care

- Local hospices and hospitals with palliative care programs will provide education on request.
- Center to Advance Palliative Care
<http://www.capc.org/>
- Coalition for Compassionate Care
<http://coalitionccc.org/nursing-homes.php>
- American Academy of Hospice and Palliative Medicine
www.aahpm.org
- End of Life/Palliative Education Resource Center
www.eperc.mcw.edu

Additional Palliative Care Resources

- **Get Palliative Care**
<http://getpalliativecare.org>
- **National Consensus Project for Palliative Care**
www.nationalconsensusproject.org/guidelines_download2.aspx
- **Palliative Dementia Care Resources**
www.pdcronline.org/index.php
- **Symptom Management Resources**
www.cancer.gov/cancertopics/pdq/supportivecare/lasthours/healthprofessional/page2
www.promotingexcellence.org/tools/symptom_management.html

Section Two

Palliative Care “Fast Fact Sheet”

PALLIATIVE CARE

“FAST FACT SHEET”

STATISTICAL DATA...

- Approximately 90 million Americans are living with serious and life-threatening illnesses, and this number is expected to more than double over the next 25 years with the baby boomers.
- By 2020, the number of people living with at least one chronic illness will increase to 157 million.
- Approximately 68 percent of Medicare costs are related to people with 4 or more chronic conditions – the typical patient who would benefit from palliative services. 7 out of 10 Americans die from chronic disease.
- Approximately 6,000,000 people in the United States could benefit from palliative care.

WHAT IS PALLIATIVE CARE?

Palliative care (pronounced pal-lee-uh-tiv) is an interdisciplinary medical specialty that focuses on preventing and relieving suffering and supporting the best possible quality of life for patients and their families facing serious illness. Palliative care is provided by a team of doctors, nurses and other professionals who work together with a patient's other doctors to provide an extra layer of support. It aims to relieve suffering in all stages of disease and is not limited to end of life care. Palliative services, including setting patient-centered achievable goals for medical care and aggressive symptom management, should be routinely offered alongside curative, rehabilitative and disease modifying treatments for patients with serious illnesses. Palliative care is frequently misperceived as synonymous with hospice services. Hospice is a health care delivery system under which support and services are provided to a patient with a terminal illness where the focus is on comfort rather than curing an illness. Thus, hospice can be considered a program that delivers palliative care to patients at the end of life, while palliative care can be appropriately offered to patients at any time along the trajectory of any type of serious illness.

WHY CONSIDER PALLIATIVE CARE?

Palliative care, when initiated early in the disease course, has been shown to improve clinical services, quality of care and survival outcomes. Palliative treatment approaches strive to achieve the following patient goals:

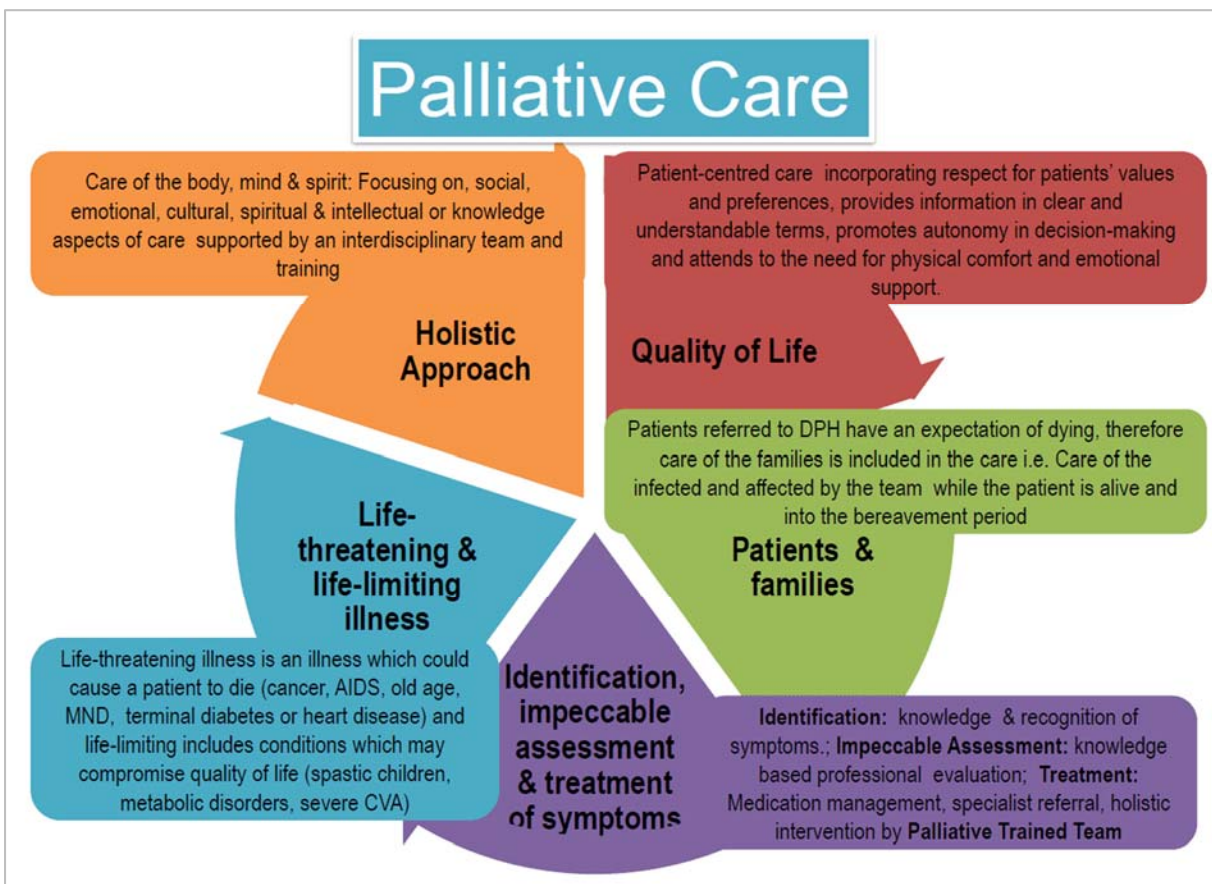
- Pain and symptom control: Your palliative care team will identify your sources of pain and discomfort. These may include problems with breathing, nausea, fatigue, depression, insomnia, or bowel or bladder. Then the team will provide treatments that can offer relief. These might include medication, counseling, and massage therapy or other alternative therapies and techniques.
- Communication and coordination: Palliative care teams are extremely good communicators. They put great importance on communication between you, your family and your doctors in order to ensure

that your needs are fully met. These include establishing goals for your care, help with decision-making and coordination of care.

- Emotional support: Palliative care focuses on the entire person, not just the illness. The team members caring for you will address any social, psychological, emotional or spiritual needs you may have.
- Family/caregiver support: Caregivers bear a great deal of stress too, so the palliative care team supports them as well. This focused attention helps ease some of the strain and can help you with your decision making.

HOW TO “GET THE BALL ROLLING”?

Palliative care can be available with a doctor’s order in a number of places. These include hospitals, outpatient clinics, long-term care facilities, hospices or home. SIMPLY ASK FOR IT...



Section Three

Palliative Care Workgroup: Clinician Guidelines

Sample Description of Position

Palliative Care Clinician Consultant —Skilled Nursing Facility

Title: Consulting Clinician - Palliative Care

Requirements: Licensed Physician, Nurse Practitioner, Physician Assistant or equivalent, with experience or certification as outlined below

Purpose of the Position: The person in this position is responsible for the provision of Palliative Care consultations and follow-up within the SNF

Position Responsibilities:

- Provide consultation services in palliative care to skilled and custodial residents.
- Facilitate clarification of resident and family goals of care.
- Consult with the attending physician and the Interdisciplinary Team (IDT) to establish a written plan of care at intervals specified in the plan.
- Facilitate access to appropriate supportive care services.
- Education of staff and coworkers.
- Full and appropriate documentation of patient care services to support professional billing for these services.
- Availability for on-call coverage for symptom management and psychosocial crises, at the request of the attending physician and/or IDT.
- Participation in interdisciplinary team meetings to review active cases.
- Assist in the development, review and updating of policies and procedures concerning Palliative Care.
- Perform other duties as requested.
- Adhere to the HIPAA requirements and the practice of confidentiality regarding residents, families, staff, and the organization.

Position Qualifications:

- Licensure in good standing with the appropriate licensing board or agency
- Current liability insurance
- Cooperation with facility credentialing procedures
- Certificate of Added Qualification in Hospice & Palliative Medicine or comparable
 - or
- At least two years' experience working on an interdisciplinary team in a Palliative Care setting (e.g., hospice, hospital palliative care team, etc.)

Specific Skill Set for Palliative Care Competencies

- Communication
- Team-Based Collaboration
- Symptom Management
- Psychosocial Assessment
- Medical Ethics
- Conflict Resolution
- Advance Care Planning
- End-of-Life Care

Palliative Care Physician Program

Operational Protocols

SAMPLE

In an effort to ensure team communication, enhanced public relations and quality resident services, the following is a recap of established operational protocols.

- ❖ **ORDERS FOR CONSULT:** Admitting nurse will include “Palliative Care Physician Consult” on the admission order OR may be requested at a later date by any of the treating disciplines upon approval from the primary physician.
- ❖ **COMMUNICATION OF THE CONSULT ORDER:**
 - Charge nurse will communicate the order to the Palliative Care Physician via phone or fax.
 - Nursing will create an alert to ensure that the order has been executed within the timeframe noted in the Policy and Procedures
- ❖ **COMMUNICATION WITH ATTENDING PHYSICIAN:**
 - Dr. _____ will maintain communication directly with the attending physician regarding any recommended additions or deletions to the resident’s treatment plan. *(Or...the protocol may otherwise state that the nurse will contact the attending physician regarding the Palliative Care Physician’s recommendations)*
 - Prior to ordering any special medications or treatments, Dr. _____ will communicate with the Charge Nurse.
- ❖ **GENERAL COMMUNICATION:**
 - Weekly contact between Dr. _____, and Director of Nursing.
 - Discussion with IDT prior to major changes in care plan (i.e.: change in advanced directives, etc.).
- ❖ **MEETING SCHEDULE:**
 - IDT/ Care Plan Conference upon request

SAMPLE
(Place on Facility Letterhead)

(Date)

Dear (Attending physician),

_____ (facility) _____ is committed to providing optimal care to all residents that enter our facility. We are pleased to announce our new relationship with our Palliative Care focused (*may be "Certified"*) physician, Dr. _____. Dr. _____ is the consulting physician and is available to see identified patients with this special need. She/he will work very closely with our interdisciplinary team members. Please note that Dr. _____ will only attend to those patients who have a consulting referral from you, the attending physician. She/he is interested in assisting all physicians of those residents that may benefit from a palliative care consult. In addition, Dr. _____ will also attend IDT/Care Plan Conferences upon request. We believe that this approach will further the quality patient services that _____ (facility) _____ strives for. Please feel free to call me at _____ (phone number) _____ if you have any questions or concerns regarding this new relationship.

Thank you for the care that you provide,

(Name)
Administrator

Supportive Care of the Dying: A Coalition for Compassionate Care

Organizational Assessment: Personnel Competency / Performance

The competency statements in this document are derived from the messages of the participants in the Living and Healing During Life -threatening Illness research work. They were described by participants as important competencies for caregivers to possess. They are presented along with assumptions about their use.

Objectives:

- To describe competencies required for care giving professionals who care for those affected by life - threatening illness
- To build on the Data from Living and Healing During Life- threatening illness in developing those competencies
- To create a set of measurable criteria and standards of performance

Assumptions:

- Criteria must be flexible and adaptable
- Organizations already have tools that can be modified to include these criteria and feedback mechanisms
- Criteria must include non-burdensome evidence strategies

Definitions:

- Performance: Includes knowledge, skills, capability, and consistent demonstration of indicator.
- Evaluation of Performance: Objective criteria with feedback from appropriate sources including self.

Areas:

Competency areas are drawn from the Modified City of Hope Questionnaires

Physical Spiritual Emotional

Relationship

Communication and sub categories System Negotiation

Care Delivery

Continuity of Care

Supportive Care of the Dying: A Coalition for Compassionate Care Competency Standards

These standards are written so they may be applied to all professionals who provide care at the end of life. This includes physicians, nurses, unlicensed personnel, social workers, therapists, spiritual care staff, volunteers, and others as appropriate within their scope of practice. It is assumed that these are supplementary to competencies required of the person to provide excellent clinical care. Evidence of competency and performance may be obtained as follows:

- Observation of person's performance
- Interview / feedback from patients and families
- Case presentations
- Self-rating
- Peer review
- Chart reviews of specified patients

We recommend review of performance annually, semiannually, or with significant evidence of excellence in performance and / or opportunities for performance improvement. This feedback mechanism will assist professionals to continue to develop their competencies and create an organizational environment of outstanding care for those facing the end of life.

These competencies are described as core competencies for **ALL** professional caregivers since all practice areas may deal with death and dying.

COMPETENCY FOCUS	DESCRIPTION OF COMPETENCY
Pain and Symptom Management	<p>Appropriately manages patient pain and other distressing physical symptoms of disease, illness or treatment in a timely manner and achieves outcomes acceptable to the patient / family.</p> <p>Management may include referral to appropriate specialist and / or acceptance and support of the patient's decision to include complementary therapies in treatment.</p>
Emotional	<p>Supports patient and family expression of emotional needs. Listens actively, supports as appropriate, and refers to support groups, other patients and families with similar conditions, and / or professionals with expertise in this area. May use open-ended questions such as "How are you doing? How are things going in your life? What, if anything, are you feeling anxious about?"</p>
Psychosocial	<p>Provides an environment to support patient and family expression of psychosocial needs. Listens actively, supports as appropriate, and refers to support groups, other patients and families with similar conditions, and / or professionals with expertise in this area. Integrates this area with each interaction. May use open-ended questions such as "How are you doing? How are things going in your life? How have things changed for you in your life? How are your spirits?"</p>
Spiritual / Cultural	<p>Manages interactions to support patient and family expression of spiritual needs and strengths and cultural practices. Creates environment that allows integration of dialogue about spiritual issues within care experience. Refers to spiritual care staff and community resources as congruent with patient / family values.</p> <p>Communicates cultural care preferences to others. May use questions such as "What is the meaning of this illness to you and for your life? What lessons would you want to share? How has your sense of time changed? What strength have you called upon as you go through this illness? What are the culturally specific care parameters you wish us to observe?"</p>

COMPETENCY FOCUS	DESCRIPTION OF COMPETENCY
Relationship - Family and Community	Addresses desires and needs for support from family and friends. Determines if there has been a change in family communication. Facilitates family communication of specific issues by structure of interactions. Provides anticipatory guidance for family as they focus on their relationships. This may include reconciliation of relationships. Provides helpful tools and / or refers for assistance with family communication. May use questions such as "How have things been within your family? What messages do you want to give to each other before death occurs? How much change has occurred with your social relationships outside the family?"
Honoring Patient Care Wishes	Understands and communicates patient and family end of life care wishes prior to crises or impending death. Honors wishes as care goals change from cure to comfort care. Only carries out interventions that make a difference for patient comfort and / or recovery. Supports patient and family when treatments are refused. Provides welcoming environment for family to stay with patient.
Dying and Death	Identifies those who are approaching last days of living. Communicates honestly to patient / family about approaching death and gifts of last days. Speaks of death as natural process not failure of treatment. Determines patient / family wishes regarding place of death and seeks to have death occur where desired. Assists family to give patient permission to die, to say "good bye", and to bring reconciliation to family relationships.

COMPETENCY FOCUS	DESCRIPTION OF COMPETENCY
After Death	Prepares family for events that occur immediately following death, i.e. select funeral home, make funeral arrangements, notify agencies such as SRS, Medicare, Attorney who handles Estate, financial issues, canceling appointments etc. Hints: This could be presented to the family in a packet of information.
Bereavement	Manages interactions with the bereaved that support communication of clinical concerns and questions as appropriate. Actively initiates referrals for support during bereavement.
Relationship	Establishes rapport with patient and family. Is viewed as "present, really listening, caring, and trustworthy". Initiates contact with bereaved family as appropriate to relationship.
Communication	Is available physically and mentally for patient and family communication. Delivers difficult information in honest clear manner. Maintains hope by focusing on palliative care when cure no longer possible. Focuses on helping patient / family live in way meaningful to them.
Teaching	Assesses for knowledge and questions. Refers to appropriate resources for additional information and support. Provides anticipatory guidance about illness, treatments, possible outcomes, and health system issues.
Team Collaboration	Provides care with a team approach that includes patient and family as integral and essential members of the care team.

Section Four

Introduction to Palliative Care for Residents and Families

INTRODUCTION
TO
PALLIATIVE CARE
FOR
RESIDENTS AND FAMILIES

CAHF



What is Palliative Care?

- Palliative care (pronounced: pal-lee-uh-tiv) is specialized medical care for people with serious illnesses. It focuses on providing patients with relief from the symptoms, pain, and stress of a serious illness - whatever the diagnosis.
- The goal is to improve quality of life for both the patient and the family.

Who Needs Palliative Care?

- Palliative care is for persons who may suffer from pain, stress or other symptoms due to a serious illness. These include, but are not limited to:
 - Cancer, cardiac disease, respiratory disease/distress, kidney failure, Alzheimer's, HIV/AIDS, amyotrophic lateral sclerosis (ALS), multiple sclerosis and more.
- Palliative care can be provided at any stage of illness and along with treatment meant to cure you or you loved one.

Curative Care vs. Palliative Care

- Curative care is directed at healing or curing a disease...like taking an antibiotic for a bladder infection, or Vitamin C if you have scurvy.
- Palliative care involves offering care that helps relieve the symptoms, but does not cure or treat the cause of a disease...like getting a massage for a stiff neck and sore shoulder which is caused by a ruptured disc in the cervical spine. The massage helps alleviate some of the pain, but does not cure the spinal defect.

Expected Benefits of Palliative Care

Relief from symptoms, such as:

- Pain
- Shortness of breath
- Fatigue
- Constipation/Diarrhea
- Nausea/Vomiting
- Loss of appetite
- Difficulty sleeping



Expected Benefits of Palliative Care

- Palliative care helps you carry on with your daily life.
- It improves your ability to go through medical treatments.
- It helps you better understand your condition and your choices for medical treatment.
- In short, you can expect the **best possible quality of life.**

Who Provides Palliative Care?

- Palliative care is provided by a team of doctors, nurses, social workers and other specialists who work together with a patient's other doctor(s) to provide an extra layer of support.
- It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.
- The care team may also include, clergy, massage therapists, pharmacists, nutritionists and others as needed per specific patient needs.

What About my Doctor?

- The palliative care team works in partnership with you own doctor(s) to provide an extra layer of support for you and patient and family.
- The team provides expert symptom management, extra time for communication and help navigating the health system.

Where Can I Receive Palliative Care?

Palliative Care is provided in a variety of settings:

- Hospitals
- Outpatient clinics
- Home
- Hospice
- Long term care facilities (skilled nursing homes)

Who Pays for Palliative Care?

- Most insurance plans, including Medicare and Medical, cover palliative care.
- If cost is a concern, a social worker or financial consultant from the palliative care team can assist.

How Do I Get Palliative Care?

Ask for it!

Tell your doctors, nurses, family and caregivers that you want **palliative care**.

Palliative Care Matters



<http://getpalliativecare.org/videos-podcasts-livechats/>

Resources

- Hospice and Palliative Nurses Association
www.hpna.org/DisplayPage.aspx?Title=Patient/Family%20Teaching%20sheets
- Get Palliative Care
<http://getpalliativecare.org/>
- Caring Connections
www.caringinfo.org/i4a/pages/index.cfm?pageid=1
- Coalition for Compassionate Care
<http://coalitionccc.org/>

Section Five

Resources

2014 CAHF'S QUALITY IMPROVEMENT (QI) PALLIATIVE CARE WORKGROUP RESOURCE SHEET

PALLIATIVE CARE:

- Get Palliative Care
<http://getpalliativecare.org>
- National Consensus Project for Palliative Care
www.nationalconsensusproject.org/guidelines_download2.aspx
- Palliative Dementia Care Resources
www.pdcronline.org/index.php
- Hospice and Palliative Nurses Association
www.hpna.org/DisplayPage.aspx?Title=Patient/Family%20Teaching%20sheets
- The Conversation Project
www.theconversationproject.org
- The Coalition for Compassionate Care
<http://coalitionccc.org/nursing-homes.php>
<http://coalitionccc.org/tools-resources/decision-guides>
- Center to Advance Palliative Care
<http://www.capc.org>
- American Academy of Hospice and Palliative Medicine
www.aahpm.org

COMPETENCIES IN PALLIATIVE CARE:

- Hospice and Palliative Medicine Core Competencies (Version 2.3)
<http://download.cahf.org/document.aspx?dt=member&dn=/quality/HospicePCMedicineCoreCompetencies.pdf>
- Specialist Palliative Care Nursing Practice Competency Standards
http://download.cahf.org/document.aspx?dt=member&dn=/quality/Specialist_PCNursing_CompetencyStd.pdf

END OF LIFE:

- Caring Connections
www.caringinfo.org/i4a/pages/index.cfm?pageid=1
- National Institute for Nursing Research
www.ninr.nih.gov/newsandinformation/conversationsmatter/conversationsmatter-patients#.U_5DqvmwJQw
- Symptom Management Resources
www.cancer.gov/cancertopics/pdq/supportivecare/lasthours/healthprofessional/page2
www.promotingexcellence.org/tools/symptom_management.html
- End of Life/Palliative Education Resource Center
www.eperc.mcw.edu
- End of Life Nursing Education Consortium (ELNEC)
www.aacn.nche.edu/elneec