Hospice & Palliative Care Association of New York State
Palliative Care Information Act Resource Center

Introduction

The **HPCANYS Palliative Care Information Act Resource Center** is a one-stop source of information that will serve as a guide for the treating physician or nurse practitioner as they provide information and counseling concerning palliative care and end-of-life options for patients diagnosed with a terminal illness.

The resource provides comprehensive answers to key questions such as what the provisions of Palliative and/or Hospice care actually are, where to find a palliative care provider and what the benefits of Palliative Care are for the patient, their family and the referring physician. The resource also provides diagnosis criteria for when the determination of a Palliative Care or Hospice referral is appropriate as well as guidance for initiating the conversion with the patient and/or the family.

Palliative Care Information Act (PCIA)

Effective February 9, 2011, Chapter 331 of the Laws of 2010 (commonly known as the Palliative Care Information Act) amended the Public Health Law by adding section 2997-c, which requires physicians and nurse practitioners to offer terminally-ill patients information and counseling concerning palliative care and end-of-life options. Under the law, information and counseling concerning palliative care and end-of-life options must be provided to patients with an illness or condition that is reasonably expected to cause death within six months. When the patient lacks medical decision-making capacity, the information and counseling must be provided to the person who has authority to make health care decisions for the patient.

Summary of the PCIA law

- PCIA requires health care practitioners caring for a patient diagnosed with a terminal illness to offer said patient or their surrogate information and counseling on available options for palliative and end-of-life care.
- The obligation to provide such information and counseling can be fulfilled by the primary physician, or by referral or transfer to another appropriate health care practitioner.
- Information can be provided verbally, or in a written document; practitioners can create their own written documents.
- Information and counseling would not have to be provided to a patient who does not want it.

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I. What is Palliative Care & how is it different from Hospice?

- **Question: What is Palliative Care?**

Palliative Care Definitions

Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patients and family members, helping with decision-making and providing opportunities for personal growth. Palliative care can be rendered along with life-prolonging treatment or as the main focus of care. Such care is appropriate to those suffering with cancer, heart conditions, liver failure, renal failure, Alzheimer's disease, spinal cord injuries, and a number of other conditions.

Palliative care is medical care provided by an interdisciplinary team, including the professions of medicine, nursing, social work, chaplaincy, counseling, nutrition, rehabilitation, pharmacy, therapists, and other health care professions. It further aims to identify and address the physical, psychological, spiritual, and practical burdens of illness.

Palliative care affirms life by supporting the patient and family's goals for the future, including their hopes for cure or life-prolongation, as well as their hopes for peace and dignity throughout the course of illness, the dying process and death. Palliative care aims to guide and assist the patient and family in making decisions that enable them to work toward their goals in the course of one's illness, condition or injury.

Palliative care is integral to all health care delivery system settings (hospital, emergency department, nursing home, home care, assisted living facilities, outpatient and non-traditional settings). The palliative care team collaborates with professional and informal caregivers in each of these settings, in order to ensure coordination, communication and continuity of care across institutional and home care settings. Palliative care is appropriate for all patients from the time of diagnosis with a life-threatening or debilitating condition, regardless of the patient's age.
Reference: National Consensus Project

Palliative care, as defined by the PCIA law, is "health care treatment, including interdisciplinary end-of-life care, and consultation with patients and family members, to prevent or relieve pain and suffering and to enhance the patient's quality of life, including hospice care**."**

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- **Question: What is Hospice?**

Hospice definitions

Hospice is a model of service that employs a multidisciplinary team who provides appropriate skilled, compassionate care to patients *and* their families so that they receive the support, help and guidance they need to meet the challenges of serious illness. In Hospice the unit of care is

the family; the Hospice team works with the patient and family to develop a personalized plan of care that incorporates what is important to the patient and the caregiver and emphasizes quality of life to assist patients to live as fully and comfortably as possible.
Reference: Hospice & Palliative Care Association of NYS (HPCANYS)

When medical care cannot offer a cure, hospice provides care, comfort and support for persons with life-limiting conditions as well as their families. The hospice team works to make the person comfortable and relieve their symptoms and pain for the entire length of their illness.
Reference: CaringInfo.org

Every hospice patient has access to a hospice volunteer, registered nurse, social worker, home health aide, and chaplain (also known as the interdisciplinary team). For each patient and family, the interdisciplinary team writes a care plan with the patient/family that is used to make sure the patient and family receive the care they need from the team. Typically, full-time registered nurses provide care to about a dozen different families. Social workers usually work with about twice the number of patients/families as nurses. If needed, home health aides, who provide personal care to the patient, will visit most frequently.

All visits, however, are based on the patient and family needs as described in the care plan and the condition of the patient during the course of illness. The frequency of volunteers and spiritual care is often dependent upon the family request and the availability of these services. Travel requirements and other factors may cause some variation in how many patients each hospice staff serves.
Reference: National Hospice & Palliative Care Organization (NHPCO)

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- **Question: How is Palliative Care different from Hospice?**

Palliative care is whole-person care that relieves symptoms of a disease or disorder whether or not it can be cured. You can receive palliative care at any stage of a serious illness, whether that illness is potentially curable, chronic or life-threatening. Hospice is a specific type of palliative care for people who likely have six months or less to live, if the disease runs its normal course. In other words, hospice care is always palliative, but not all palliative care is hospice care.
Reference: PalliativeDoctors.org

Palliative care helps patients and families make medical decisions and choose treatments that are in line with their goals. Palliative care may be provided at any time during a person`s illness, even from the time of diagnosis. Hospice always provides palliative care. However, hospice is focused on terminally ill patients—people who no longer seek treatments to cure them. Palliative care is appropriate at any point in a serious illness and can be provided at the same time as treatment that is meant to cure.
Reference: GetPalliativeCare.org

The goal of palliative care is to prevent and relieve suffering, and to support the best possible quality of life for patients and their families, regardless of their stage of disease or the need for other therapies, in accordance with their values and preferences. Palliative care affirms life by supporting the patient and family's goals for the future, including their hopes for cure or life prolongation, as well as their hopes for peace and dignity throughout the course of illness, including the dying process and death. Palliative care aims to guide and assist the patient and family in making decisions that enable them to work toward their goals during whatever time

they have remaining. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care.
Reference: American Academy of Hospice & Palliative Medicine (AAHPM)

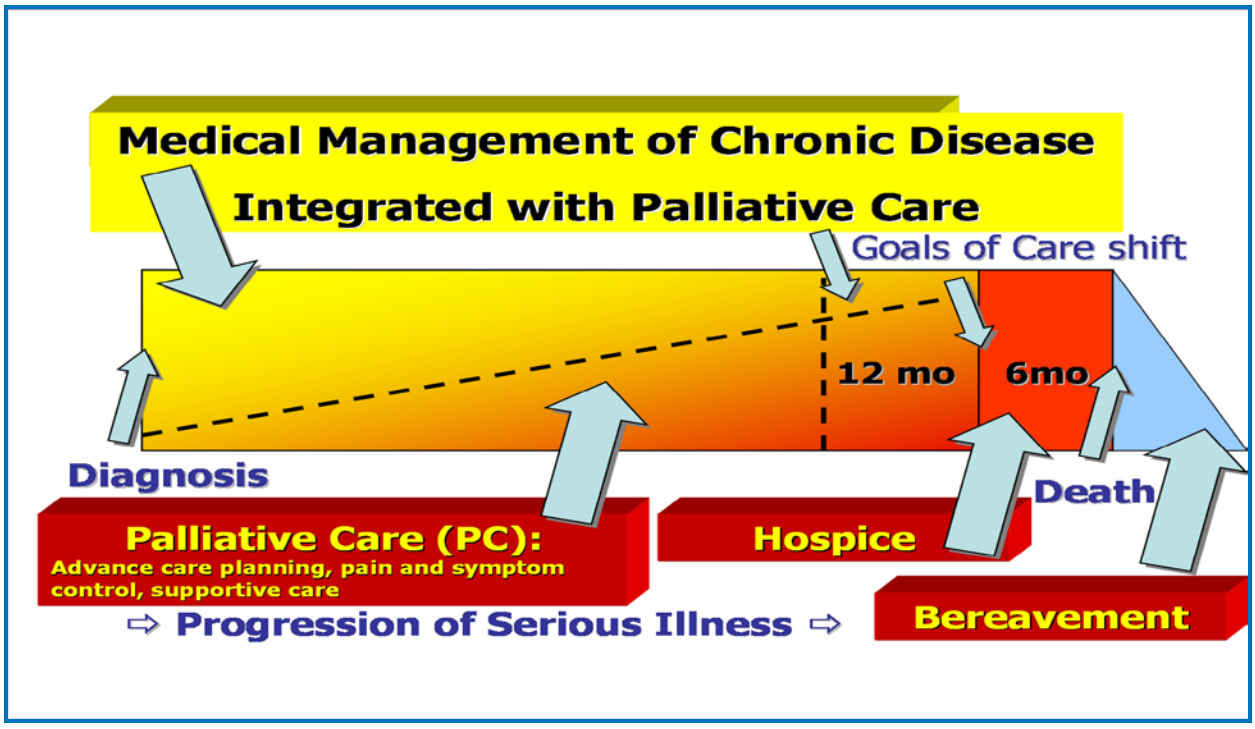
Many hospice programs have added palliative care to their names to reflect the range of care and services they provide, as hospice care and palliative care share the same core values and philosophies. As defined by the World Health organization, palliative care seeks to address not only physical pain, but also emotional, social and spiritual pain to achieve the best possible quality of life for patients and their families. Palliative care extends the principles of hospice care to a broader population that could benefit from receiving this type of care earlier in their illness or disease process.
Reference: Hospice & Palliative Care Association of NYS (HPCANYS)

Palliative Care and Hospice Care ~ What is the difference?

Question	Palliative Care	Hospice Care
Who can receive this care?	Anyone with a serious illness, regardless of life expectancy	Someone with an illness with a life expectancy measured in months not years
Can I continue to receive treatments to cure my illness?	You may receive palliative and curative care at the same time	Treatments and medicines aimed at relieving symptoms are provided by hospice
Does Medicare pay?	Some treatments and medications may be covered	Medicare pays all charges related to hospice
Does Medicaid pay?	Some treatments and medications may be covered	In 47 states, Medicaid pays all charges related to hospice
Does private insurance pay?	Some treatments and medications may be covered	Most insurance plans have a hospice benefit
Is this a package deal?	No, there is no ‘palliative care’ package	Medicare and Medicaid hospice benefits are package deals
How long can I receive care?	This will depend upon your care needs and insurance coverage	As long as you meet the hospice’s criteria of an illness with a life expectancy of months not years
What organization provides these services?	• Hospitals • Hospices • Nursing Facilities • Health Care Clinics	• Hospice organizations • Hospice programs based out of a hospital • Other health care organizations

Where are services provided?	• Home • Assisted living facility • Nursing facility • Hospital	• Usually, wherever the patient resides, in their home, assisted living facility, nursing facility, or hospital. • Some hospices have facilities where people can live, like a hospice residence, or receive care for short-term reasons, such as acute pain or symptom management.
Who provides these services?	It varies. However usually there is a team similar to the hospice team.	A team – doctor, nurse, social worker, chaplain, volunteer, home health aide and others.
Do they offer expert end-of-life care?	This varies, be sure to ask	Yes, staff are experts in end-of-life care

The following graph provides a visual representation of how Palliative Care fits into the continuum of Medical care from diagnosis to death



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II. Appropriateness

- **Question: Who needs Palliative Care? How do I know this person is appropriate for Palliative Care?**

Is your patient appropriate for a palliative care referral? A palliative care consultation will assist you in managing complex pain, symptoms, co-morbidities, patient/family communication and

other issues. The following criteria have been developed to help you assess whether a palliative care consultation would be beneficial to you and your patient.

Presence of a serious, chronic illness:

- Declining ability to complete activities of daily living
- Weight loss
- Multiple hospitalizations
- Difficult to control physical or emotional symptoms related to serious medical illness
- Patient, family or physician uncertainty regarding prognosis
- Patient, family or physician uncertainty regarding goals of care
- Patient or family requests for futile care
- DNR order conflicts
- Use of tube feeding or TPN in cognitively impaired or seriously ill patients
- Limited social support and a serious illness (e.g. homeless, chronic mental illness)
- Patient, family or physician request for information regarding hospice appropriateness
- Patient or family psychological or spiritual distress

Intensive Care Unit Criteria

- Admission from a nursing home in the setting of one or more chronic life-limiting conditions (e.g. dementia)
- Two or more ICU admissions within the same hospitalization
- Prolonged or difficult ventilator withdrawal
- Multi-organ failure
- Consideration of ventilator withdrawal with expected death
- Metastatic cancer
- Anoxic encephalopathy
- Consideration of patient transfer to a long-term ventilator facility
- Family distress impairing surrogate decision-making

Oncology Criteria

- Metastatic or locally advanced cancer progressing despite systemic treatments with or without weight loss and functional decline;
    - Karnofsky < 50 or ECOG > 3
    - Progressive brain metastases following radiation
    - New spinal cord compression or neoplastic meningitis
    - Malignant hypercalcemia
    - Progressive pleural/peritoneal or pericardial effusions
    - Failure of first or second-line chemotherapy
    - Multiple painful bone metastases
    - Consideration of interventional pain management procedures
    - Severe prolonged pancytopenia in the setting of an untreatable hematological problem (e.g. relapsed leukemia)

Emergency Department Criteria

- Multiple recent prior hospitalization with same symptoms/problems
- Long-term care patient with Do Not Resuscitate (DNR) and/or Comfort Care (CC) orders

- Patient previously enrolled in a home or residential hospice program
- Patient/caregiver/physician desires hospice but has not been referred
- Consideration of ICU admission and or mechanical ventilation in a patient
    - with metastatic cancer and declining function
    - with moderate to severe dementia
    - with one or more chronic diseases and poor functional status at baseline

    Reference: GetPalliativeCare.org

Questions to determine whether a palliative care referral might be right for your patient

1. Has your patient been diagnosed with any of the following:

- Cancer
- Congestive heart failure
- Chronic obstructive pulmonary disease (COPD)/emphysema
- Kidney failure
- Liver failure
- Dementia

2. Is your patient experiencing symptoms related to diagnosis such as:

- Pain
- Shortness of breath
- Fatigue
- Anxiety
- Depression
- Lack of appetite
- Nausea
- Constipation

3. Has your patient experienced any of the following:

- Frequent emergency room visits
- Multiple admissions to the hospital (3 or more within 12 months) with the same symptoms
- A turning point in the illness where treatment is no longer working
- Eating problems associated with an advanced illness

4. Does your patient need help with health related:

- Future planning
- Decision making
- Emotional support
- Spiritual or religious support

Reference adapted from: GetPalliativeCare.org

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Palliative Performance Scale (PPS) has been found useful for purposes of identifying and tracking potential care needs of palliative care patients, particularly as these needs change with disease progression.

The Palliative Performance Scale uses five observer-rated domains correlated to the Karnofsky Performance Scale (100-0). The PPS is a reliable and valid tool and correlates well with actual survival and median survival time for cancer patients. It has been found useful for purposes of identifying and tracking potential care needs of palliative care patients, particularly as these needs change with disease progression. Large validation studies are still needed, as is analysis of how the PPS does, or does not, correlate with other available prognostic tools and commonly used symptom scales.

PALLIATIVE PERFORMANCE SCALE (PPS)

%	Ambulation	Activity Level Evidence of Disease	Self-Care	Intake	Level of Consciousness	Estimated Median Survival in Days (a)	(b)	(c)
100	Full	Normal *No Disease*	Full	Normal	Full	N/A	N/A	108
90	Full	Normal *Some Disease*	Full	Normal	Full			
80	Full	Normal with Effort *Some Disease*	Full	Normal or Reduced	Full			
70	Reduced	Can't do normal job or work *Some Disease*	Full	As above	Full	145		
60	Reduced	Can't do hobbies or housework *Significant Disease*	Occasional Assistance Needed	As above	Full or Confusion	29	4	
50	Mainly	Can't do any	Considerable	As above	Full or	30	11	41

	sit/lie	work E*xtensive Disease*	Assistance Needed		Confusion			
40	Mainly in Bed	As above	Mainly Assistance	As above	Full or Drowsy or Confusion	18	8	
30	Bed Bound	As above	Total Care	Reduced	As above	8	5	
20	Bed Bound	As above	As above	Minimal	As above	4	2	6
10	Bed Bound	As above	As above	Mouth Care Only	Drowsy or Coma	1	1	
0	Death	-	-	-	--			

a. Survival post-admission to an inpatient palliative unit, all diagnoses (Virik 2002).
b. Days until inpatient death following admission to an acute hospice unit, diagnoses not specified (Anderson 1996).
c. Survival post admission to an inpatient palliative unit, cancer patients only (Morita 1999).

Reference: End of Life / Palliative Education Resource Center

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- **Question: What is the benefit of Palliative Care?**
  - **For patient & family**

The patient and/or family may worry that agreeing to palliative care means giving up hope for a cure. That is not the case at all. In fact, palliative care can help *you* cope with aggressive treatments by getting your pain and symptoms under control to help you fight the disease. Palliative care helps you achieve quality of life as you define it.

The palliative doctor and team explain the pros and cons of your treatment options so you can make informed decisions about how you want to manage your illness and symptoms, and live your life. They also can provide emotional and spiritual support and resources. In other words, they are concerned about you, not just your illness. Palliative care translates into tangible benefits. There is a wealth of evidence that people who receive palliative care are highly satisfied, as are their loved ones.

Many studies show palliative care controls pain; controls common symptoms of serious illness such as fatigue, anxiety, shortness of breath, nausea, depression and constipation; improves quality of life. For instance, one study found patients with cancer who receive palliative care were more likely to complete chemotherapy treatment and reported a higher quality of life than those who didn't receive palliative care.

Reference: PalliativeDoctors.org

The findings of a recent study called, *'Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer'* which was reported in the New England Journal of Medicine Article state that compared with patients receiving standard care, patients who received palliative care early after diagnosis not only experienced significant and meaningful improvements in both quality of life and mood but also received less aggressive care at the end of life and experienced longer survival times by approximately 2 months.
Reference: New England Journal of Medicine 2008, Vol. 363 (8), pg. 733-742.

- **Key Elements/Benefits of Palliative Care:**

1. Pain and symptom control, psychosocial distress, spiritual issues and practical needs are addressed with patient and family throughout the continuum of care.
2. Patients and families obtain the information they need in an ongoing and understandable manner, in order to grasp their condition, prognosis and treatment options. In this process, their values and goals are elicited over time; the benefits and burdens of treatment are regularly reassessed; and decision-making about care is sensitive to changes in the patient's condition.
3. Genuine coordination of care across settings is ensured through regular and high-quality communication between providers at times of transition or changing needs, and through effective continuity of care that utilizes the techniques of case management.
4. Both patient and family are prepared for the dying process and for death, when it is anticipated. Hospice options are explored, opportunities for personal growth are enhanced, and bereavement support is available for the family.

Reference: American Academy of Hospice & Palliative Medicine (AAHPM)

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- **Question: What is the benefit of Palliative Care?**
  - **For the provider**

Palliative medicine complements the attending physician's care when comfort, counseling and quality of life become increasingly important. Palliative medicine consultations benefit referring physicians when:

- Pain and debilitating symptoms are difficult to control
- Ethical decision-making is unclear
- Complex physical, psychological and social suffering requires extensive evaluation and close follow-up

Reference: Center to Advance Palliative Care (CAPC)

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III. Timing

Question: When is a Hospice referral appropriate based on diagnosis?

Determining Appropriateness for a Hospice Referral

Predicting a life-expectancy of 6 months or less usually involves a significant, documented deterioration in physical status/function such as weight loss or decreased function and/or an end-stage disease. Decline may also be due to refusal of treatments, medications or hospitalization aimed at improving or stabilizing an advanced disease.
A patient can be appropriate for hospice even without a specific end-stage disease *(see DECLINE IN STATUS).*

- **AMYOTROPHIC LATERAL SCLEROSIS** (ALS): Patients tend to have a constant overall rate of decline, whether rapid or slow. They should have 1 **OR** 2 **OR** 3 below:

1. CRITICALLY IMPAIRED BREATHING CAPACITY occurring over the past 12 months with **ALL** of the following: a) dyspnea at rest; b) supplemental O2 at rest; c) no ventilator or ventilator only for comfort. A vital capacity <30% is supportive, if available **OR**
2. RAPID PROGRESSION AND CRITICAL NUTRITIONAL IMPAIRMENT with **ALL** of the following in the past 12 months: a) bed-bound; b) barely or unintelligible speech; c) pureed diet; d) major assist in all ADLs; e) insufficient oral intake; f) continuing weight loss; g) NO ARTIFICIAL NUTRITION except to relieve hunger **OR**
3. RAPID PROGRESSION AND LIFE THREATENING COMPLICATIONS with **ONE** of the following in the past 12 months: a) recurrent aspiration pneumonia; b) upper UTI; c) sepsis; d) recurrent fever in spite of antibiotics; e) stage 3/4 decubitus ulcers

- **CANCER**: should have 1 **OR** 2

1. DISTANT METASTASES AT DIAGNOSIS **OR**
2. PROGRESSION FROM EARLIER STAGE TO METASTATIC DISEASE with **EITHER**: a) failure of treatment; **OR** b) refusal of further treatment
3. NOTE: may be eligible on diagnosis of small-cell lung cancer, brain cancer, and pancreatic cancer if treatment is not sought

- **DEMENTIA OF ALZHEIMERS TYPE**: patients should have 1 **AND** 2

1. ≥ STAGE 7 on FAST SCALE: a) unable to ambulate and dress and bathe without assistance; b) incontinent of urine and stool; c) 6 or less intelligible words/day **AND**
2. ONE OF THE FOLLOWING IN THE PAST 12 MONTHS: a) aspiration pneumonia ; **OR** b) upper UTI; **OR** c) septicemia; **OR** d) multiple stage 3/4 decubitus ulcers; **OR** d) recurrent fever on antibiotics; **OR** e) weight loss >10% in past 6 months/ albumin <2.5

- **AIDS**: patients should have 1 **AND** 2; factors from 3 are supportive

1. CD4+ < 25 (2 or more assays at least 1 month apart) OR VIRAL LOAD> 100,000 **AND ONE** OF THE FOLLOWING: a) CNS lymphoma; **OR** b) wasting with weight loss>10%; **OR** c) MAC ,untreated or treatment ineffective or refused; **OR** d) PML; **OR** e) systemic lymphoma with partial chemo response; **OR** f) visceral Kaposi's sarcoma unresponsive to treatment; **OR** g) renal failure and no dialysis; **OR** h) cryptosporidium; **OR** i) toxoplasmosis unresponsive to treatment **AND**
2. PERFORMANCE SCALE < 50% (KPS or PPS)
3. SUPPORTIVE: a) diarrhea > 1 year; b) albumin <2.5; c) ongoing substance abuse; d) age >50; e) resistance to antiretrovirals or prophylactic RX; f) advanced AIDS dementia; g) toxoplasmosis; h) CHF; i) advanced liver disease

- **HEART DISEASE**: patients should have 1 **AND** 2; factors from 3 are supportive

1. OPTIMAL TREATMENT AND EITHER NOT A CANDIDATE FOR /OR REFUSE SURGERY **AND**
2. NYHA class IV (discomfort with any physical activity; symptoms of CHF angina at rest). (EF =/≤ 20% if available)
3. SUPPORTIVE: a) symptomatic arrhythmias resistant to treatment; b)previous arrest/CPR; c) unexplained syncope; d) brain embolus from heart; e) HIV

- **LIVER DISEASE**: patients should have 1 **AND** 2; factors from 3 are supportive

1. PT > 5 SEC. OVER CONTROL OR INR. 1.5 **AND** Albumin < 2.5 **AND**
2. ONE OF THE FOLLOWING: a) refractory ascites or non-compliance; **OR** b) spontaneous bacterial peritonitis; **OR** c) hepato-renal syndrome; **OR** d) refractory encephalopathy or non-compliance; **OR** e) recurrent esophageal variceal bleeding despite treatment
3. SUPPORTIVE: a) weight loss>10%; b) muscle wasting/loss of strength; c) continued alcohol consumption; d) hepatocellular cancer; e) HBsAg positive; or f) hepatitis C refractory to treatment

- **LUNG DISEASE**: patients should have 1 **AND** 2; factors in 3 are supportive

1. Dyspnea at rest and minimal exercise tolerance (with FEV1 <30% IF AVAILABLE) and progression of disease with increased ER visits, hospitalizations or MD home visits (documented serial decrease in FEV1 40 ml/year if available) **AND**
2. pO2 <55 mmHg ON ROOM AIR **OR** O2 SAT < 88 ON O2 **OR** Pco2 >50 mm Hg
3. SUPPORTIVE: a) cor pulmonale; b) weight loss.10% in past 6 months; c) HR > 100/min at rest

- **KIDNEY DISEASE**: patients should have 1 **AND EITHER** 2 **OR** 3; factors in 4 and 5 are supportive

1. Not seeking dialysis or transplant or stopping dialysis **AND**
2. Creatinine clearance < 10 cc/min (<15 FOR DIABETICS) OR LESS THAN 15 cc/min WITH CHF (< 20 cc/min FOR DIABETICS) **OR**
3. CREATININE > 8 mg/dl (> 6 FOR DIABETICS)
4. SUPPORTIVE FOR ACUTE RENAL FAILURE: a) mechanical ventilation; b) cancer; c) chronic lung disease; d) advanced heart disease; e) advanced liver disease; f) sepsis; g) AIDS; h) albumin < 3.5; i) cachexia; j) platelet ct < 25,000; k) DIC; l) GI bleeding
5.SUPPORTIVE FOR CHRONIC RENAL FAILURE: a) uremia b) oliguria (< 400cc/day); c) K+ > 7 with treatment; d) pericarditis; e)hepatorenal syndrome; f) intractable fluid overload

- **STROKE**: patients should have 1 **AND** 2; factors in 3 are supportive

1. KPS/PPS < 40 **AND**
2. INADEQUATE NUTRITION WITH **ONE** OF THE FOLLOWING: a) weight loss > 10% in 6 months or 7.5% in 3 months; **OR** b) albumin < 2,5; **OR** c) aspiration pneumonia not responsive to speech therapy intervention; **OR** d) inadequate caloric intake counts; **OR** e) severe dysphagia and **NO** artificial feeding
3. SUPPORTIVE: any of the following in the previous 12 months: a) aspiration pneumonia; b) upper UTI; c) sepsis; d) refractory decubitus ulcer 3/4; e) recurrent fever on antibiotics

- Note: specific CT findings on hemorrhagic or embolic strokes may support poor prognosis

- **COMA:** patients with **ANY 3** of the following on DAY 3 of coma: a) abnormal brainstem response; b) no verbal response; c) no withdrawal response to pain; d) creatinine > 1.5. For supportive factors see 3 under STROKE

- **DECLINE IN CLINICAL STATUS** (formerly FAILURE TO THRIVE and/or DECLINE IN FUNCTION) This category is for documented, irreversible decline over time from a known baseline

1. Progression of Disease. No specific number of variables is needed.
A. Clinical: 1) recurrent infections; 2) weight loss not from reversible cause; 3) falling albumin or cholesterol; 4) dysphagia with recurrent aspiration and/or poor intake
B. Symptoms: 1) dyspnea with increased RR; 2) intractable cough; 3) intractable nausea/vomiting; 4) intractable diarrhea; 5) increasing pain on treatment

C. Signs; 1) systolic BP<90 or postural hypotension; 2) ascites; 3) venous, arterial or lymphatic obstruction; 4) edema; 5) pleural/ pericardial effusion; 6) weakness; 7) change in LOC
D. Laboratory (NOT required): 1) increasing CO2 or decreasing pO2 or O@ sat; 2) increasing calcium, creatinine or LFTs; 3) increasing tumor markers; 4) progressively high or low Na or high K
E. Performance Scale <70 due to disease
F. Increasing visits to ER or MD or Hospitalizations
G. Decline in Fast Scale (≥7A)
H. Progressive Dependence in ADLs
I. Progressive Decubitus Ulcers 3/4 in spite of RX

2. **Non-Disease specific guidelines**; A **AND** B are required
A. performance score < 70 (Stroke and AIDS require lower PPS) **AND**
B. Dependence on assistance for 2 or more ADLs: 1) feeding; 2) ambulation; 3) continence; 4) transfer; 5) bathing; 6) dressing
C. Comorbidities likely to contribute to < 6 months life expectancy: 1) COPD; 2) CHF; 3) ischemic heart disease; 4) diabetes; 5) neuralgic disease; 6) kidney failure; 7) liver disease; 8) cancer; 9) AIDS; 10) dementia

Reference: CompassionandSupport.org

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IV. Communication

- **Question: When is it appropriate to have the conversation about Palliative Care with the patient?**
- **Question: When do I have the conversation with the patient?**

Following is a framework for having a conversation about Palliative Care with the patient based on hope and preparation by using clinical scenarios (below) to develop strategies and prepare for pitfalls.

Scenario 1: Encourage but Do Not Impose the Dual Agenda of Hoping and Preparing
Embracing a dual approach of hoping for the best and preparing for the future progression of an illness helps physicians join with patients and families, yet plan medical care that is responsive to a range of potential outcomes for the patient.
Dr.: *It's good for me to know about your hopes. It helps me get to know you better. Do you also want to talk about your concerns if things do not go as we hope?*
Patient: *I'm really committed to trying this new treatment, and I feel like you are kind of giving up on me with this "preparing for the future progression" stuff.*
Dr.: *I share your hope that the new treatment will benefit you. I want you to have the best medicine available. I talk about hoping for the best and preparing for the future with all my patients who are seriously ill. Preparing for future possibilities doesn't mean I'm giving up on you; it helps me arrange the best medical care for you, no matter what happens.*

When physicians initiate a conversation about preparing for the future progression of an illness, patients and family members may react with fear, sadness, anxiety, or anger. Blocking or ignoring such emotions sends a nonverbal message that the physician is uncomfortable in discussing the worst and discourages patients from honestly discussing their concerns. There can be positive consequences for patients who prepare for the worst, which physicians can

underscore, and these can be powerful motivators. By preparing for the worst—by making a living will, naming a health care proxy, preparing financial matters, or settling family affairs—patients can address fears, clarify priorities, and strengthen relationships with loved ones, all components of a good death identified in empirical studies of patients with life-threatening illnesses. Furthermore, some patients may be thinking about the worst but are afraid to discuss it for fear of frightening their family or disappointing their physician. Naming and discussing these concerns, which often deal with spiritual and existential issues, is an important first step for patients. Physicians can also benefit from discussing the future progression of the illness. These discussions allow physicians to feel that they are being honest with patients and, if done in the context of a supportive relationship, can increase patient trust. Patients and families who prepare for a range of outcomes may be less likely to blame their physicians for the consequences of their disease progression.

Scenario 2: Give Equal Air Time to Hoping and Preparing
Dr.: *I want to work with you, and I will do everything I can to optimize your chances. I am hoping for the best. I think that, at the same time, we need to prepare for the future in case the treatment is not effective.*
Patient*: Hope is really important to me.*

By articulating hope and preparation at the outset the physician gives the patient permission to discuss a wide range of topics. An introductory statement such as "I have found it helpful to hope for the best and, at the same time, prepare for the future possibilities" allows the patient to discuss the topic he feels is most important or is most comfortable with. For patients like Mr. J., who want to discuss hopes first, we recommend following the patient's lead to fully explore hopes and place those hopes in the context of the patient's disease process. Other patients may need to prepare for their potential death before they can commit wholeheartedly to active treatment.

Scenario 3: Align Patient and Physician Hopes
Dr.: *Could you tell me more about what you are hoping for? That will help me do a better job for you.*
Hope is a critical element for coping with illness. Most patients expect and want physicians to be advocates for health and longevity. Patients frequently cite hope as the most important element of their coping and seek clinicians who will search every avenue of hope but Physicians also want to hope for the best. Many physicians pursued medicine because they wanted to cure diseases, make patients feel better, and help relieve suffering. Articulating hopes for extending a patient's life can affirm this aspect of medicine. Providing hope to patients is psychologically gratifying because patients and families are often grateful to doctors who hope. Shared hopes offer physicians an opportunity to align with their patient.

The following table, **Responding to Hopes and Fears** uses sample statements and physician responses that suggest ways to deepen the conversation and better understand patient concerns after diagnosis. The examples show how physicians can respond to both hopes and fears as they discuss hoping for the best and preparing for the worst with their patients. To use this strategy effectively, physicians should explore patients' hopes and fears and respect patients' boundaries. Note that the suggested physician responses do not move immediately toward solving problems or reassuring. Premature reassurance can make patients feel their concerns are not heard.

Patient Says:	Physician Responds:
I hope that the treatment will help me out.	I'm also hoping that the treatment will help you. If it works, what will be the most important thing for you to do? I wonder, also, if you would be willing to talk about what we should do in case the treatment doesn't work.
I'm concerned that talking about what might happen will be overwhelming.	Well, talking about what might happen can be frightening at first, but most patients I have worked with have found it helpful in the long run.
I'm worried that talking about 'what happens if' would be giving up.	I understand your concern, but we are not talking about giving up
I don't want to talk about what I'm worried about.	Okay, I realize that talking about worries can be a hard thing to do. If you do want to talk about these issues in the future, I would be open to it.
I hope that I can live a little longer.	I hope you can live longer too. What would be most important for you in that time?

Reference Adapted from: Annals Internal Medicine 2003, Back A. L., *Hope for the best, and Prepare for the Worst*, Vol.138 (5) pgs. 439- 443

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- **Question: How do I begin the conversation?**

Following is a framework for **Patient-Centered Interviewing**

How might the physician begin a conversation about Palliative Care with the patient? One strategy is to strive to understand both the patient's disease and illness. Disease refers to a biological, pathophysiological process. Illness refers to the patient's experience. The physician can assess a patient's illness experience by asking about 4 dimensions—Feelings, Ideas, Function and Expectations.

Clinical Case: You admit Mary, a new patient, to the hospital. Mary has end-stage, metastatic pancreatic cancer. She has not seen a physician since she was given a terminal diagnosis 6 months ago at another institution. She is nutritionally depleted and has an apparent gastrointestinal obstruction causing significant bloating and discomfort. While you are admitting her she informs you that she is curing herself by drinking fresh fruit and vegetable juices. She refuses to discuss advanced directives because she "Does not trust you."

Patient-centered Interviewing: How might you begin to develop a working relationship with Mary? One strategy is to strive to understand both Mary's disease and her illness. Disease refers to a biological, pathophysiological process. Illness refers to the patient's experience. You can assess a patient's illness experience by asking about 4 dimensions—Feelings, Ideas, Function and Expectations. The acronym FIFE can be a helpful reminder.

F = FEELINGS related to the illness, especially fears

- What are you most concerned about?
- Do you have any specific fears or worries right now?
- I imagine you have had many different feelings as you have coped with this illness.
- Sometimes people have fears that they keep to themselves and don't tell their doctor.

I = IDEAS and explanations of the cause of a symptom or illness

- What do you think might be going on?
- What do you think this pain means?
- Do you have ideas about what might have caused this illness?

F = FUNCTIONING, the illness' impact on daily life

- How has your illness affected you day to day?
- What have you had to give up because of your illness?
- What goals do you have now in your life? How has your illness affected your goals?
- How does this illness affect important people in your life?

E = EXPECTATIONS of the doctor & the illness

- What do you expect or hope I can do for you today?
- Do you have expectations about how doctors can help?
- What do you hope this treatment will do for you?
- What are your expectations about what might happen with this illness?

Reference: End of Life/Palliative Education Resource Center

Talking About Treatment Options and Palliative Care: A Guide for Clinicians At Time of Diagnosis: Begin to Understand Your Patient's Priorities and Goals

When patients first learn that they have a potentially life-limiting illness their focus is on curing the disease. However, there are opportunities as an initial plan of care is developed to discuss the benefits of advance care planning and the differences between curative and palliative care. *Introducing the concept of palliative care as care focused on alleviating symptoms even as you work to cure the illness will allow you to continue referencing palliation of symptoms, optimizing functional capacities and the importance of psychosocial support for the patient and the family.*

The questions in this document, when introduced during a conversation about treatment options can provide clinicians with information about what is important to the patient. Simply asking one or two of these questions can lead to future discussions about palliative care and present the patient with an opportunity to explore the topic with you when they are ready.

As we think about treatment options, what is one thing about you that you think is important to share with me?

- What is your biggest fear when you think about your diagnosis?
- What is your biggest fear about the treatments we have discussed?
- What does quality of life mean to you?
- As things progress, how much do you want to know about your disease and all the various treatment options? With whom do you want me to share information, and how much?

When Treatment May Not Be Working: Exploring End-of-Life Options

At some point, it may become apparent that continued treatments are not likely to offer any specific therapeutic benefit for your patient. One question that is often used to frame a discussion about ending curative treatment protocols is **"Would you be surprised if your patient died in the next six to twelve months?"** If the answer is no, it may be time to begin the transition away from treatments with curative intent and emphasize beneficial disease modifying therapies and palliative care.

In addition to the questions listed above, the following can help you begin/continue the dialogue with your patient.

- Are you comfortable?
- Do you feel that any of your treatments are causing you more harm than good?
- Do you feel like you have good "quality of life" right now?
- If we could do one thing, other than cure your illness, to bring you quality of life, what do you think it would be?
- Let's talk again about how much information you want to have about your disease.

Explaining Treatment Options

Sometimes "the way we've always done it" is not always the most effective way to communicate with patients. The goal is to make sure you are "heard" by patients, that they understand their options, and that they are able to make choices about their care that meets their individual needs. Here are some new approaches, offered in counterpoint to some of the more traditional ways of communicating with patients.

Traditional Approaches	New Approaches
XYZ treatment has a 5% success rate.	In my experience this treatment works for one in twenty people. For those people, they live an average of X number of months/years.
We can tip the odds in your favor by trying this treatment.	This treatment might give you a slightly better chance of survival than if we didn't do it.
Some patients experience XYZ side effects as a result of the treatment protocol.	You can expect the following side effects in relation to this treatment. I will work with you to manage these side effects as best I can. However, if the side effects become too troublesome, we can talk about other options, including stopping or changing the treatment.
This is what I recommend…	I can explore options with you, but decisions about how to care for you are yours.
Do you have any questions?	I've presented a lot of information to you, what questions do you have?
At some point we may have to look at hospice as an option.	With the disease you have, it is very likely that hospice care will be the best option at some time in the future. We can discuss this over time so that you can make decisions that best suit your needs.

Understanding Your Patient's Needs: Responding to Patient/Caregiver Inquiries
Listening to what your patient is saying or not saying is a crucial part to understanding their needs. Questions a patient may ask you are listed below, along with what they might be thinking and truly wanting to know.

When a Patient/Caregiver Asks…	They Might be Thinking…
What are my chances?	Realistically, how likely is it that this will work?
What would you do if you were me?	I am overwhelmed, and I need help or guidance in making these decisions.
How long do I have?	I feel like I am dying… *Or* I am scared about facing death, but I don't have the words to express this… *Or* I really want to know what a realistic time line is so I can make good choices and get things in order…
What are the options?	This isn't working. I want to try something else.

Reference: CaringInfo.org

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- **Question: How do I engage the family in the conversation?**

A cornerstone procedure in Palliative Care is leadership of family meetings to establish goals of care, typically completed at a time of patient change in status, where the value of current treatments needs to be re-evaluated. As with any procedure, preparation is essential to ensure the best outcome.

Following is a framework overview for '**Preparing for the Family Meeting**.'
Data Review: Review the medical history relevant to the current medical situation (e.g. history of disease progression, symptom burden, past treatments, treatment-related toxicity, and prognosis).

- Review all current treatments (e.g. renal dialysis, artificial nutrition, antibiotics) and any positive and/or negative treatment effects.
- Review all treatment options being proposed
- Determine the prognosis with and without continued disease-directed treatments. Prognostic information includes data concerning future patient function (physical/cognitive), symptom burden, and time (longevity).
- Solicit and coordinate medical opinions about the utility of current treatments among consultants and the primary physician. If possible, families need to hear a single medical consensus—all relevant clinicians should be contacted and consensus reached prior to the

meeting. If the consultants do not agree, then prior to the family meeting they should meet to negotiate these differences and attempt to reach consensus regarding the plan. If there is no consensus, a plan should be developed for how to describe these differences to families.

- If the patient lacks capacity, review any Advance Directive(s), with special attention to discover if the patient has named a surrogate decision maker, and if the patient has indicated any specific wishes (e.g. DNR status, 'no feeding tubes').
- Seek out patient/family psychosocial data. Focus on psychological issues and family dynamics (e.g. anger, guilt, fear) potentially impacting decision making. These issues may be long-standing, or due to the current illness. **Note:** talking to the patient's social worker, bedside nurses, and primary and consulting physicians can help you get a better sense of the family and how they make decisions.
    - Review what transpired in prior family meetings.
    - Learn about particular cultural/religious values and/or or social/financial issues that may impact decision making.

Information Synthesis Based on your review of the medical and prognostic data, make an independent determination of which current and potential tests/treatments will improve, worsen, or have no impact on the patient's function/quality of life (physical/cognitive) and time (longevity).

Meeting Leadership Leading a family meeting requires considerable flexibility to ensure that all relevant participants have the opportunity to have their points of view expressed. Though it is useful to have one person designated as the main orchestrator and coordinator of the meeting, the essential skills for making a family meeting successful can come from more than one participant. These skills include:

- Group facilitation skills.
- Counseling skills.
- Knowledge of medical and prognostic information.
- Willingness to provide leadership/guidance in decision making.

Invitations A decisional patient can be asked who he/she wants to participate from his/her family/community, including faith leaders; in general it is wise not to set any arbitrary limits on the number of attendees. The medical care team should likewise decide who they want to participate. **Note:** it is important not to overwhelm a family with too many health professionals. On the other hand, a physician from the primary team as well as a nurse and social worker should attend when possible; these individuals can help ensure the consistency of information as well as help deal with complicated dynamics. If the patient has a long-time treating physician whom he/she trusts, this person should ideally be present.

Setting The ideal setting is private and quiet, with chairs arranged in a circle or around a table. Everyone should be able to sit down if they wish. For non-decisional patients, the clinical team should negotiate with the surrogate whether or not to have the meeting in the presence of the patient.

The Pre-Meeting Meeting The participating health care members should meet beforehand to confirm: a) the goals for the meeting (e.g. information sharing, specific decisions sought), b) who will be the meeting leader to start the meeting, and c) likely sources of conflict and initial management strategies.

Authors: David E Weissman MD, Timothy Quill MD, and Robert M Arnold MD

Reference: End of Life / Palliative Education Resource Center

Following is a review of the early steps of an actual family meeting: **Starting the Conversation**

1. **Introductions & setting goals for the meeting**
    - The meeting leader begins the meeting by introducing him or herself, and suggesting that each person present (medical team and family/community) introduce themselves including their relationship to the patient.
    - The meeting leader should summarize the meeting goals (e.g. *We are here to discuss next steps in the care of Mr. Jones*) and ask the family to confirm these goals and/or add other agenda items.

    Note: if you do not know the patient or family well, take a moment to build relationship. Ask a non-medical question such as *I am just getting to know you. I had a chance to look at your chart and learn about your medical condition but it does not say much about your life before you got sick. Can you tell us about the things you liked to do before you got sick?* Similarly, if the patient is not able to participate in the meeting, ask family to describe the patient prior to his becoming ill: *As we get started, can you describe what Mr. Jones was like before he became ill?*
2. **Determine what the patient/family already knows:** This step is essential as it guides you in providing a synthesis of the medical information (see below). Always invite the patient and all family members to provide their understanding of the medical information.

    Examples of opening lines:
    - *Tell me what the doctors have told you about your condition?*
    - *Can you describe for me your sense of how things are going?*
    - For patients who have been declining from a chronic illness, you can ask*: Tell me about the past 3-6 months: what types of changes have you noted?* The patient or family will typically describe changes in terms of function (physical or cognitive) and quality of life.
3. **The Medical Review:** Once you know what the patient/family understands, you are in a good position to confirm their understanding, or provide new information/correct misunderstandings.

    First, ask if you can bring them up-to-date about what is going on; asking shows politeness and also signals that they should attend to what you are trying to say. The clinician most closely aligned with the patient's ongoing treatment should begin this discussion, supplemented with information from consulting services if relevant. Do not provide information using medical jargon or in an organ system approach (e.g., *The creatinine is improving, but there is a new pleural effusion and the heart rate has become irregular*).

    A more patient-centered approach is to provide a succinct summary of the current condition, without any medical jargon, focusing on the issues of most importance, which are usually function/quality/time. Give a 'bottom-line' statement: 'getting worse,' 'not going to improve,' 'dying and time is likely very short.'

    The worsening weakness and pain you describe is from the cancer which is growing despite the chemotherapy. *You are telling me that despite the recent hospitalization, you are not able to do as much around the house; unfortunately your lung disease is getting worse despite all our best treatments. Despite our best efforts, your wife's brain injury from the car crash is getting worse. She can no longer stay awake or move her arms/legs.*

4. **Using the 'D word' if relevant:** when a patient is clearly deteriorating and death is likely within the next days to weeks, or even a few months, it is appropriate to use the word *dying* in the conversation. Both patients and surrogates find that saying the word *dying*, if done compassionately, is helpful in clearing what is often a confusing and frightening situation. *I'm afraid we have run out of options to shrink the cancer. Based on your declining function, I believe you are dying.*

5. **Silence** Whether or not you use the word *dying*, when you have presented bad news (such as information about disease progression), the next step is for you to allow silence, and let the family/patient respond. In truth, no matter what you might imagine the response from the patient/family to be once the bad news is delivered, you really cannot predict their emotional reaction (e.g. relief, anxiety, anger, regret, fear). This silence can be uncomfortable; resist the urge to fill it with more facts as they will not be heard. Not all patients/families express emotions at this point and instead respond practically (*Well, what happens next then?*). This is fine, but you need to wait, silently, to see what response the patient/family demonstrates. In addition, even practical questions have underlying emotions (*Are you sure?* Or – *There must be something you can do?*). It is important to respond to both the factual aspect of the question (*Yes I am sure.* Or – *There are no more effective treatments available*.), as well as the emotional level (*I wish I had better news for you.* Or – *I wish our treatments worked better than they do.).*

When the patient/surrogates openly acknowledge that current treatments are no longer effective, that death is coming, they will generally ask one or all of the following questions: *How long? What will happen? Will there be suffering? What do we do now?* Your response at this point should be to address prognosis in terms of time, function, and symptoms, as best you can.
Authors: David E Weissman MD, Timothy Quill MD, and Robert M Arnold MD
Reference: End of Life / Palliative Education Resource Center

Following is a concise overview of running a family meeting:
Moderating a Family Conference ~ Family Conference Process Steps

1. **Why are you meeting?** Clarify conference goals in your own mind. What do you hope to accomplish?
2. **Where:** A room with comfort, privacy and circular seating.
3. **Who:** Patient (if capable to participating); legal decision maker/health care power of attorney; family members; social support; key health care professionals.
4. **Introduction and Relationship Building**
    - Introduce self & others; review meeting goals; clarify if specific decisions need to be made.
    - Establish ground rules: each person will have a chance to ask questions and express views; no interruptions; identify legal decision maker; and describe importance of supportive decision making.
    - If you are new to the patient/family, spend time seeking to know the "person"—ask about hobbies, family, what is important in her or his life, etc.
5. **Determine what the patient/family already knows.** Tell me your understanding of the current medical condition? Ask everyone in the room to speak. Also ask about the past 1-6 months—what has changed in terms of functional decline, weight loss, etc.
6. **Review medical status**
    - Review current status, prognosis and treatment options.
    - Ask each family member in turn if they have any questions about current status, plan & prognosis.

- Defer discussion of decision making until the next step.
- Respond to emotional reactions (See Fast Facts #29, 59).

7. **Family Discussion with a Decisional Patient**
   - Ask the patient; 'What decision(s) are you considering?'
   - Ask each family member; 'Do you have questions or concerns about the treatment plan? How can you support the patient?'
8. **Family Discussion with a Non-Decisional Patient**
   - Ask each family member in turn: 'What do you believe the patient would choose if the patient could speak for him or herself?'
   - Ask each family member: 'What do you think should be done?'
   - Ask if the family would like you to leave room to let family discuss alone.
   - If there is consensus, go to 10; if no consensus, go to 9.
9. **When there is no consensus:**
   - Re-state: What would the patient say if they could speak? Ask: Have you ever discussed with the patient what he or she would want in a situation like this?
   - If you, as a clinician, have a firm opinion about the best plan of care, recommend it simply and explicitly, and explain why.
   - Use time as ally: schedule a follow-up conference the next day.
   - Try further discussion: What values is your decision based upon? How will the decision affect you and other family members?
   - Identify other resources: Minister/priest; other physicians; ethics committee.
10. **Wrap-up:**
    - Summarize consensus, disagreements, decisions, & plan.
    - Caution against unexpected outcomes.
    - Identify family spokesperson for ongoing communication.
    - Document in the chart – who was present, what decisions were made, follow-up plan.
    - Don't turf discontinuation of treatment to nursing.
    - Continuity – Maintain contact with family and medical team. Schedule follow-up meetings as needed.

Author(s): Bruce Ambuel PhD and David E Weissman MD
Reference: End of Life / Palliative Education Resource Center

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Question: What are the Cultural considerations for communication?

Patients' cultural backgrounds profoundly influence their preferences and needs regarding discussing bad news, decision-making, and the dying experience.

Asking about Cultural Beliefs in Palliative Care

The following offers a framework for taking a 'cultural history' to better understand a patient's and family's needs.

C – Communication. Identify the patient's preferences regarding how and to whom medical information is shared. *Some people want to know everything about their medical condition, and others do not. How much would you like to know?* For those who request that the physician discusses their condition with family members: *Would you like me to speak with them alone, or would you like to be present?* Identify main contacts to give information to about the patient's condition. Carefully explore with families requests to hide information from a patient.

U – Unique cultural values. Use respectful, curious, and open-ended questions about a patient's cultural heritage to identify their values. *Is there anything that would be helpful for me to know about how you and your family view serious illness? Are there cultural beliefs, practices, or preferences that affect you during times of significant illness?* If the patient is open to discussing death: *What concerns do you have about dying? Are there things that are important to you or your family that I should know about?*

L – Locus of decision-making. For some patients medical decision-making is communally driven rather than individualistic. Multiple family members or a community elder or leader may need to be involved, often without prior official documentation because it is assumed or understood from the patient's perspective. *Do you prefer to make medical decisions about tests and treatments yourself, or would you prefer that others in your family or community make them for you?*

T – Translators. Language barriers are extremely challenging, especially during times of severe illness. Utilize medical interpreters frequently and effectively.

U – Understanding the patient and learning as a provider. Reassess what is being heard, understood, and agreed upon frequently, from both the patient's and clinician's standpoint. Specifically confirm the patient's understanding or agreement (beyond nodding or "yes" responses). This is particularly important if a medical translator is involved as miscommunication is common even when using trained medical interpreter. *Can you tell me – in your own words – what you have heard from me and what's most important to you about what I've said?*

R – Ritualized practices and restrictions. Determine if there are specific customs the patient desires to be followed. These must be communicated to other health care providers, especially in the hospital setting. It may be necessary to advocate for the patient and negotiate with healthcare facility administrators to find an agreeable way to honor a patient's wishes. *Are there specific practices that you would like to have in the hospital or at home? Are there aspects of medical care that you wish to forgo or have withheld because of your cultural beliefs? Is anything discouraged or forbidden?* If the patient is approaching death, and willing to discuss it: *Are there specific practices that are important to you at the time of death or afterwards that we should know about?*

E – Environment at home. Given that a majority of hospice care happens in the patient's home environment, respectfully explore whether there are any needs that can be met by the health care system, and how open the patient, family or community is to receiving care at home. Recognize that patients may be hesitant to voice needs, or resistant to accepting help from outside the community. Even if a trusting, collaborative relationship has developed between a patient/family and clinicians in the hospital, this may not immediately translate into the home setting. With the patient's permission, expectations about cultural-specific aspects of a patient's care should be explicitly communicated to care providers outside the hospital.

Author(s): Hillary Lum MD, PhD and Robert Arnold MD
Reference: End of Life / Palliative Education Resource Center

Strategies for Culturally Effective End-of-Life Care: Differences in beliefs, values, and traditional health care practices are of particular relevance at the end of life. Health care providers and patients and families may not have shared understandings of the meaning of illness or death and may not agree on the best strategies to plan for the end of life or to alleviate pain and suffering. Values so ingrained in physicians as to be unquestioned may be alien to patients from different backgrounds. It is important for Physicians to be aware of values, perspectives,

and biases that are derived from their own culture of origin and from the biomedical world view of their professional training. Medicine itself is a cultural system with its own specific language, values, and practices that must be translated, interpreted and negotiated with patients and their families. This article describes two cases that raise issues about cross-cultural end-of-life practice and suggests strategies for negotiating common problems.
Reference**:** Strategies for Culturally Effective End-of-Life Care
American College of Physicians–American Society of Internal Medicine 2002, Vol. 136 (9), pg. 673-679

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- **Question: What are the Spiritual considerations for communication?**

The National Consensus Project (NCP) and National Quality Forum (NQF) have deemed Spiritual care an essential component to improving quality palliative care. Some patients have specific preferences or needs regarding medical care, death and dying that are based upon their religious beliefs.

FICA Spiritual History Tool

The FICA Spiritual History Tool was developed by a group of primary care physicians to help physicians and other healthcare professionals address spiritual issues with patients. The FICA tool serves as a guide for conversations in the clinical setting and can be used as a part of the conversation about Palliative Care with a patient at the time of diagnosis.

F – Faith and Belief

Do you consider yourself spiritual or religious?" or "Do you have spiritual beliefs that help you cope with stress?" If the patient responds "No," the health care provider might ask, "What gives your life meaning?" Sometimes patients respond with answers such as family, career, or nature.

I – Importance

"What importance does your faith or belief have in our life? Have your beliefs influenced how you take care of yourself in this illness? What role do your beliefs play in regaining your health?"

C – Community

"Are you part of a spiritual or religious community? Is this of support to you and how? Is there a group of people you really love or who are important to you?" Communities such as churches, temples, and mosques, or a group of like-minded friends can serve as strong support systems for some patients.

A – Address in Care

"How would you like me, your healthcare provider, to address these issues in your healthcare?"

Spiritual Assessment in Clinical Practice: This is a multimedia guide for tapping the spiritual beliefs, values, and practices important in your patients' responses to illness or stress.
Resource: George Washington Institute for Spirituality & Health

Taking a Spiritual History:

When a physician stands with a patient as they face serious illness, the physician inevitably plays a role in supporting the patient's inquiry into spiritual questions and concerns. In addition some patients have specific preferences or needs regarding medical care that are based upon their religious beliefs. The physician often plays an important role in supporting a patient's exploration of these issues. Taking a spiritual history is one way to support the patient in this exploration. The following is presents an interview framework for taking a spiritual history using the acronym SPIRIT.

S—spiritual belief system

- Do you have a formal religious affiliation? Can you describe this?
- Do you have a spiritual life that is important to you?
- What is your clearest sense of the meaning of your life at this time?

P—personal spirituality

- Describe the beliefs and practices of your religion that you personally accept.
- Describe those beliefs and practices that you do not accept or follow.
- In what ways is your spirituality/religion meaningful for you?
- How is your spirituality/religion important to you in daily life?

I—integration with a spiritual community

- Do you belong to any religious or spiritual groups or communities?
- How do you participate in this group/community? What is your role?
- What importance does this group have for you?
- In what ways is this group a source of support for you?
- What types of support and help does or could this group provide for you in dealing with health issues?

R—ritualized practices and restrictions

- What specific practices do you carry out as part of your religious and spiritual life (e.g. prayer, meditation, services, etc.)
- What lifestyle activities or practices do your religion encourage, discourage or forbid?
- What meaning do these practices and restrictions have for you? To what extent have you followed these guidelines?

I—implications for medical care

- Are there specific elements of medical care that your religion discourages or forbids? To what extent have you followed these guidelines?
- What aspects of your religion/spirituality would you like to keep in mind as I care for you?
- What knowledge or understanding would strengthen our relationship as physician and patient?
- Are there barriers to our relationship based upon religious or spiritual issues?
- Would you like to discuss religious or spiritual implications of health care?

T—terminal events planning

- Are there particular aspects of medical care that you wish to forgo or have withheld because of your religion/spirituality?
- Are there religious or spiritual practices or rituals that you would like to have available in the hospital or at home?
- Are there religious or spiritual practices that you wish to plan for at the time of death, or following death?
- From what sources do you draw strength in order to cope with this illness?
- For what in your life do you still feel gratitude even though ill?
- When you are afraid or in pain, how do you find comfort?

- As we plan for your medical care near the end of life, in what ways will your religion and spirituality influence your decisions?

Reference: End of Life / Palliative Education Resource Center

Religious traditions and their impact on healthcare decision-making: This resource for clinicians includes brief articles on common ways in which spiritual considerations might affect health care decisions from the Catholic, Protestant, Jewish, Muslim, Hindu and Sikh perspectives. Included are practical measures to consider along with issues that arise in health care settings and case examples. Resource: The George Washington Institute for Spirituality & Health

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V. Access to Palliative Care and Hospice

- **Question: How is Palliative Care paid for?**

Most insurance plans cover all or part of the palliative care treatment you receive in the hospital, as with other hospital and medical services. This is also true of Medicare and Medicaid. Drugs and medical supplies and equipment may also be covered. If costs concern you, a social worker or financial consultant from the palliative care team can help you with payment options.
Resource: GetPalliativeCare.org

Many private insurance companies and health maintenance organizations (HMOs) offer palliative care and hospice benefits. Medicare (mostly for people 65 and older) offers hospice benefits, and the extra Medicare plan (Part B) offers some palliative care benefits. Medicaid coverage of hospice and palliative care for people of limited incomes varies by state.
Resource: PalliativeDoctors.org

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- **Question: How do I find a Palliative Care provider?**

Palliative care can be provided at a hospital, a nursing home, an assisted living facility or at home. There are a number of ways to find a doctor who specializes in palliative medicine, including asking a local hospital if they have a palliative specialist.

You can also search for the availability of 'American Board of Hospice and Palliative Medicine' (ABHPM) certified palliative doctors in your area by using the AAHPM doctor finder.
Resource: American Academy of Hospice & Palliative Medicine

Locate Palliative Care Providers from any one of the following sites:

- Hospice & Palliative Care Association of NYS (HPCANYS): http://hpcanys.org/find_palliative.asp
- National Hospice & Palliative Care Organization (NHPCO): http://iweb.nhpco.org/iweb/Membership/MemberDirectorySearch.aspx?pageid=3257&showTitle=1
- Get Palliative Care: http://www.getpalliativecare.org/providers/

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- **Question: How do I find a Hospice Provider?**

You can locate Hospice providers by county in NY State here:

- Hospice & Palliative Care Association of NYS (HPCANYS): http://hpcanys.org/find_program.asp

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VI. Role

- **Question: What is the continuing role of the Primary Care provider?**

Q. If I receive palliative or hospice care, will I still be able to see my personal doctor?

A. Absolutely. Your palliative doctor coordinates care with your other doctors and helps you navigate the often-complex health care system.
Reference: PalliativeDoctors.org

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VII. Additional Resources:

NYS Department of Health offers an online resource that provides information and answers regarding the legal and compliance requirements of the PCIA as well as information on patient rights in NYS and advanced directives.
http://www.health.ny.gov/professionals/patients/patient_rights/palliative_care/

The **United Hospital Fund** offers a free guide to help facilitate palliative and end of life care discussions. Spanish, Chinese and Russian versions are also available. Family caregivers and health care providers are encouraged to review the resource, "*A Family Caregiver's Guide to Hospice and Palliative Care*," which is available at http://nextstepincare.org.

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