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## BEST PRACTICES IN CARING FOR PATIENTS WITH SERIOUS ILLNESS

- Palliative care focuses on relieving symptoms and stress to improve quality of life for patients with serious illness, regardless of stage of illness or life expectancy.
- Palliative care can be provided along with curative treatment by the frontline primary care provider or medical specialist.
- Use palliative care approaches to communication (eg, the *NURSE* framework) and pain and symptom management to improve outcomes for your seriously ill patients.
- Provide advance care planning and document the patient's wishes in advance directives.
- Refer to specialist palliative care teams when patients have refractory symptoms, are highly stressed, or have complex communication issues with family members or treatment teams.
- Refer to hospice for end-of-life comfort care when there is a prognosis of 6 months or less and the patient is ready to forgo curative treatment.

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Palliative care for people with serious illness (eg, congestive heart failure, chronic pulmonary or kidney disease, cancer, and AIDS) focuses on providing relief from symptoms and stress to improve quality of life for both the patient and the family. Palliative care can be provided along with curative treatment at any stage in the disease, regardless of the patient's life expectancy (**Box 1<sup>1,2</sup>**).

### BOX 1. FACTS ABOUT PALLIATIVE CARE<sup>1,2</sup>

Palliative care

- focuses on improving the quality of life for any patient living with a serious illness<sup>9</sup> and his or her family,
- can be delivered along with curative or disease-directed treatments,
- is appropriate at any age and at any stage of illness,
- can be delivered effectively in hospital, outpatient primary and specialist care, and home care programs.

<sup>9</sup>For example, congestive heart failure, chronic pulmonary or kidney disease, cancer, and AIDS.



People of color are less likely to receive effective palliative care. There are disparities in assessment and treatment of pain, with Black patients significantly less likely than Whites to be adequately treated for pain.<sup>3,4</sup> Compared with Whites, Black and Latino patients with serious illness report less satisfaction with provider communication, and discussions are less likely to result in care that is consistent with patient preferences.<sup>3</sup>

The primary features of palliative care are symptom management and in-depth communication (Table 1<sup>1,2,5</sup>), both of which can be provided in outpatient primary or disease specialty care.

Use palliative care approaches when conveying serious news and discussing goals of care and treatment options.

- Assess symptoms and ask patients which symptoms most affect their quality of life; plan treatment accordingly.
- Refer to specialist palliative care teams when patients are suffering from refractory symptoms or intense stress (**Resources for Patients**).
- Refer patients to hospice when their prognosis is 6 months or less and they are ready to forgo curative treatment (**Resources for Patients**). Hospice provides comfort care only, with no curative interventions, and is only appropriate at the end of life.

**TABLE 1. SKILL SETS NEEDED TO CARE FOR SERIOUSLY ILL PATIENTS<sup>1,2,5</sup>**

Frontline Clinicians	Palliative Care Specialists
<ul style="list-style-type: none"> <li>• Pain and symptom management</li> <li>• Management of uncomplicated depression and anxiety</li> <li>• Discussions about               <ul style="list-style-type: none"> <li>• what to expect; prognosis</li> <li>• patient priorities and concerns</li> <li>• matching treatment to the patient's goals</li> <li>• caregiver burden</li> <li>• code status</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Management of refractory pain and symptoms</li> <li>• Management of complex depression, anxiety, grief, and spiritual or existential distress</li> <li>• Assistance with conflict resolution regarding goals or methods of treatment:               <ul style="list-style-type: none"> <li>• within families</li> <li>• between staff and families</li> <li>• among treatment teams</li> </ul> </li> <li>• Assistance with ethical and legal aspects of care, including concerns about futility</li> </ul>

## ESTABLISH GOALS OF CARE

A goals-of-care discussion can lessen the chance that a patient will die in an ICU or receive mechanical ventilation and increase the likelihood of enrollment in hospice for more than 1 week.<sup>6</sup>

Discuss goals of care after a new diagnosis or when symptom burden, functional status, or prognosis worsens.<sup>7</sup> Present the topic and ask permission to discuss it<sup>7,8</sup>:

- *I wanted to talk about your illness, where things might be going, and what's important to you—is that okay?*
- *Would you like to talk about what all this means?*

### Step 1

Evaluate the patient's understanding of his or her illness and identify any information preferences<sup>7,8</sup>:

- *Tell me what you know about where things are with your illness right now.*
- *How much information would you like about what might be coming ahead with your illness?*

### Step 2

If the patient asks to know what to expect in the future, tell the truth. If the patient asks how long he or she has to live, respond with averages:

- *On average, a person at your stage of lung cancer lives for about 6 months. Some people live longer than that and others don't live quite that long. We will do everything we can to keep you on the long side of that number.*

Pause after sharing this information; it is a lot to take in. Allow silence and wait for the patient to respond.

### Step 3

Ask about worries and concerns. Most people are worried that they will be in pain or have other symptoms and suffering. Reassure them that modern medicine has very effective treatments for symptoms and that you will make sure he or she is comfortable<sup>7,8</sup>:

- *What is most important for you in your life right now? Do you have any specific goals?*

## BOX 2. SAMPLE NURSE STATEMENTS FOR RESPONDING TO EMOTIONS<sup>9</sup>

<b>Naming</b>	"It sounds like you're worried" or "Some people would be angry"
<b>Understanding</b>	"That helps me understand how you feel" or "I can't imagine what _____ is like"
<b>Respecting</b>	"It's obvious how much you care about _____" or "You're doing a really good job monitoring your diet"
<b>Supporting</b>	"I will be here no matter what you decide" or "I will make sure that I follow-up with _____"
<b>Exploring</b>	"Tell me more about why you're worried about _____" or "What do you mean when you say _____?"

- *What are your biggest fears or worries in terms of your health?*
- *Is there anything specific you want to avoid? Are there any abilities you can't imagine living without?*
- *If you become much sicker, what interventions would you want (or not want)?*
- *What does your family know about your illness and your wishes?*

Use core communication skills when delivering a serious diagnosis and discussing goals of care and treatment options (**Resources for Providers**).

## EXPRESS SUPPORT

Respond to the patient's concerns in a way that conveys understanding and support (**Box 2**).<sup>9</sup> The *NURSE* framework is one patient-centered approach to empathetic communication.

## ENGAGE PATIENTS AND FAMILIES IN ADVANCE CARE PLANNING

All patients should be offered the opportunity to talk about advance care planning, and specifically whom they would trust to make medical decisions on their behalf if they were unable (either temporarily or permanently) to make their own (ie, health care proxy, **Box 3**<sup>10-12</sup>). Once the proxy is appointed, remind the patient to discuss these issues with the proxy, including instructions on what the patient would want if too sick to make decisions and not expected to recover. It is critical to enter the name and contact information for the health care proxy into the patient's medical record. Revisit these issues periodically,

especially with changes in health status or with life changes, such as a marriage or divorce. Public-use advance care planning tools are available in English and Spanish (**Resources for Patients**).

## ASSESS AND MANAGE SYMPTOMS

People with serious illness experience a range of physical and psychological symptoms (**Table 2**<sup>13-23</sup>).

For patients with any serious illness, routinely assess symptoms with validated tools such as the **Palliative care Outcome Scale (POS)** or **POS Symptom list (POS-S)**, or the **Edmonton Symptom Assessment System (ESAS)**.<sup>24,25</sup> Evaluate identified symptoms for time of onset, duration, alleviating and provoking factors, quality/character, severity, and related factors.

### Ask patients which symptoms are most troublesome

Understanding which symptoms are most upsetting can help determine patient goals and priorities.<sup>26</sup>

Some general approaches to managing common symptoms in serious illness, including nonpharmacologic interventions, are described in **Table 3**<sup>1,27,28</sup>.

## WHEN TO REFER TO A SPECIALIST PALLIATIVE CARE TEAM

Specialist palliative care is provided by a trained team of doctors, nurses, and other specialists who work together with a patient's other clinicians to provide an extra layer of support. Refer those who have refractory symptoms, are highly stressed, or have complex communication issues with family members or treatment teams (**Resources for Patients**).

### BOX 3. ADVANCE DIRECTIVES IN NEW YORK STATE<sup>10-12</sup>

#### Health Care Proxy

- Is a standard form approved under New York State (NYS) law.
- Designates an agent (an adult, 18 years of age or older) who is legally authorized to make decisions with the medical team if a physician determines that the patient is unable to.

#### Living Will or Medical Directive

- Can take the form of a personal letter, a worksheet, or a statement in the space designated on the health care proxy form itself.
- Provides clear and convincing evidence of a patient's health care wishes.
- Captures the most useful information: the patient's preference for either comfort measures or life-prolonging treatments if he or she becomes seriously ill and permanently unable to recognize or interact with their loved ones.

- Applies ONLY when the patient loses capacity to make medical decisions.

#### Do Not Resuscitate (DNR) Order (prehospital setting)

- Instructs providers and emergency workers not to revive the patient if he or she is in respiratory or cardiac arrest.

#### Medical Orders for Life-Sustaining Treatment (MOLST)

- Is a medical order form that tells providers and emergency medical workers the patient's wishes for life-sustaining treatment.
- Applies as soon as a patient consents to the orders in it and a physician signs it.
- Travels with the patient across health care settings.
- Must be reviewed and renewed by a physician at least every 7 days in hospitals, every 60 days in nursing homes, and every 90 days in other community settings.

See **Resources—Communication Skills Training** for guidance on discussing advance care planning.

**TABLE 2. SYMPTOMS EXPERIENCED BY PATIENTS WITH COMMON SERIOUS ILLNESS<sup>13-23</sup>**

Symptom	Cancer	CHF	COPD	CKD	Dementia	AIDS
Pain	✓	✓	✓	✓	✓	✓
Breathlessness	✓	✓	✓	✓	✓	✓
Fatigue or lack of energy	✓	✓	✓	✓	✓	✓
Anorexia	✓	✓	✓	✓	NA	✓
Nausea or vomiting	✓	✓	✓	✓	✓	✓
Constipation	✓	✓	✓	✓	✓	✓
Anxiety or nervousness	✓	✓	✓	✓	NA	✓
Depression or sadness	✓	✓	✓	✓	NA	✓
Dry mouth	✓	✓	✓	✓	NA	✓
Sleep disturbance	✓	✓	✓	✓	NA	✓

CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease; CKD, chronic kidney disease; NA, no data available.

#### BOX 4. MEDICARE PART A HOSPICE BENEFITS<sup>29</sup>

**Medicare hospice benefits** are available to patients who meet *all* of the following conditions:

- Eligible for Medicare Part A (hospital insurance).
- The patient's doctor and the hospice medical director certify that the patient has 6 months or less to live if the illness runs its normal course.
- The patient signs a statement choosing hospice care instead of other Medicare-covered benefits to treat the terminal illness.<sup>a</sup>
- Hospice care is provided by a Medicare-approved hospice program.

#### Hospice care includes

- Physician and nursing care
- Social work services

- Medical equipment and supplies
- Physical, speech, and occupational therapy
- Drugs for symptom control and pain relief
- Hospice aide
- Short-term respite care
- Home health aide and homemaker services
- Dietary counseling
- Grief and loss counseling for patient and family
- Short-term inpatient care (for pain and symptom management)
- Any other Medicare-covered services needed to manage pain and other symptoms, as recommended by the hospice team

<sup>a</sup>Medicare will continue to cover medical care not related to the terminal illness.

#### WHEN TO REFER TO HOSPICE

Hospice care can relieve suffering and improve quality of life for patients with a prognosis of 6 months or less who wish to forgo life-prolonging procedures and treatments. Hospice care is typically delivered at home and includes medical care, equipment, and supplementary services (Box 4)<sup>29</sup> (Resources—Hospice Services).

#### SUMMARY

Palliative care improves quality of life for patients of any age and at any stage of serious illness, and can be provided along with curative treatment. Use palliative care approaches to communication and pain and symptom management to improve outcomes for your seriously ill patients. ♦

**TABLE 3. GENERAL APPROACHES TO SYMPTOM MANAGEMENT IN SERIOUS ILLNESS<sup>1,27,28</sup>**

Symptom	Nonpharmacologic Interventions	Pharmacologic Interventions
Fatigue	<ul style="list-style-type: none"> <li>Occupational therapy to evaluate for energy-conserving behavioral modifications</li> <li>Physical therapy for rehabilitation or exercise program</li> </ul>	<ul style="list-style-type: none"> <li>Evaluate for secondary causes of fatigue such as depression.</li> </ul>
Pain	<ul style="list-style-type: none"> <li>Condition-specific therapy (eg, radiation for bone metastases)</li> </ul>	<ul style="list-style-type: none"> <li>Mild-moderate: NSAIDs and acetaminophen</li> <li>Neuropathic: Consider topical lidocaine, pregabalin, gabapentin.</li> <li>Cancer-related or severe: Consider opioids with a regimen to prevent constipation.</li> </ul>
Breathlessness/dyspnea	<ul style="list-style-type: none"> <li>Hypoxia-related: Oxygen</li> <li>No hypoxia: Consider nasal cannula or room fan.</li> <li>Consider referral to pulmonary rehabilitation, especially for patients with COPD.</li> </ul>	<ul style="list-style-type: none"> <li>Advanced stage illness: Consider low-dose opioids to prevent hypoxia; use doses lower than those used to treat pain.</li> </ul>
Nausea	<ul style="list-style-type: none"> <li>Assess for environmental factors.</li> </ul>	<ul style="list-style-type: none"> <li>Select agent based on underlying mechanism: <ul style="list-style-type: none"> <li>If due to stimulation of central chemoreceptors (eg, chemotherapy), consider ondansetron.</li> <li>If due to delayed gastric emptying (eg, opioids, anticholinergic medications), consider pro-kinetic agents (eg, metoclopramide).</li> <li>If due to tumor (eg, increased intracranial pressure or visceral organ involvement), consider steroids to reduce edema.</li> </ul> </li> </ul>
Constipation	<ul style="list-style-type: none"> <li>Encourage fluid intake, adequate fiber intake, and activity as tolerated.</li> </ul>	<ul style="list-style-type: none"> <li>Bowel stimulant (eg, senna); increase dose as needed. If ineffective, add osmotic agent (eg, polyethylene glycol, magnesium sulfate).</li> </ul>
Depression	<ul style="list-style-type: none"> <li>Cognitive behavioral therapy (CBT)</li> <li>Consider social support, effective communication, exercise.</li> </ul>	<ul style="list-style-type: none"> <li>Standard therapies; if prognosis is &lt;6 months, consider specialty referral for alternative therapy with more rapid onset of action.</li> </ul>
Anxiety	<ul style="list-style-type: none"> <li>Psychotherapy for interpersonal therapy or CBT. Evaluate for secondary physiologic causes such as dyspnea.</li> <li>Consider mindfulness, relaxation, and music; recommend exercise.</li> </ul>	<ul style="list-style-type: none"> <li>Use standard therapies, but keep prognosis in mind, given that several weeks are needed for full effectiveness.</li> <li>If prognosis is poor and immediate relief of acute anxiety is needed, consider short-acting benzodiazepines.</li> </ul>

## PALLIATIVE CARE QUIZ

1. A 66-year-old man returns to clinic for his CXR results. The clinical picture and imaging are very suggestive of lung carcinoma. You refer for a bronchoscopy and biopsy. The histology later confirms squamous cell lung cancer and the patient is found to have stage 4 disease.<sup>a</sup>

Which statement is correct?

- He should not be given any indication that the diagnosis may be lung cancer until the biopsy results are back.
- Questions should be answered in detail to all patients even if a patient does not want to know.
- You should ask the family what the patient would like to know before talking with the patient.
- You should not share the information with the patient, as it is not culturally appropriate to discuss death and dying.

- It is helpful to check the patient's current understanding before proceeding to explain further information at the patient's pace and wishes.
- Palliative care includes all except
  - Pain and symptom management.
  - Management of uncomplicated depression and anxiety.
  - A signed Do Not Resuscitate (DNR) order.
  - Discussions about patient priorities and concerns.
  - Matching treatment to the patient's goals.

### Answers:

- E:** It is helpful to check the patient's current understanding before proceeding to explain further information at the patient's pace and wishes. This is the first step in establishing goals of care.
- C:** A signed DNR order is not required for the provision of palliative care.

<sup>a</sup>Adapted with permission from The University of Edinburgh. Palliative Care Curriculum Toolkit: A practical guide to integrating palliative care into health professional education. [www.ed.ac.uk/files/atoms/files/curriculum\\_toolkit\\_-\\_ks\\_final\\_07\\_10\\_15\\_2\\_final.pdf](http://www.ed.ac.uk/files/atoms/files/curriculum_toolkit_-_ks_final_07_10_15_2_final.pdf). Accessed March 1, 2017.

## RESOURCES FOR PROVIDERS

### Continuing Medical Education

- CAPC (Center to Advance Palliative Care): [www.capc.org/providers/courses/](http://www.capc.org/providers/courses/) (free for CAPC members)

*Courses on communication skills, leadership support, pain management, preventing crises through whole patient care, and symptom management*

### Validated Symptom Assessment Tools

- City of Hope Professional Resource Center: [prc.coh.org](http://prc.coh.org)
- Palliative Care Outcome Scale (POS): [pos-pal.org](http://pos-pal.org)
- POS Symptom list (POS-S): [pos-pal.org/maix/pos-s-in-english.php](http://pos-pal.org/maix/pos-s-in-english.php)
- Edmonton Symptom Assessment Scale (ESAS): [www.npcrc.org/files/news/edmonton\\_symptom\\_assessment\\_scale.pdf](http://www.npcrc.org/files/news/edmonton_symptom_assessment_scale.pdf)
- New York City Health Department. City Health Information: *Detecting and Treating Depression in Adults* (depression screening tool)  
*Providing Primary Care to Transgender Adults* (depression, anxiety, substance use, and PTSD screening tools)

### Communication Skills Training

- CAPC courses: [www.capc.org/providers/courses/](http://www.capc.org/providers/courses/) (free for CAPC members)
- Compassion and Support. Medical Orders for Life-Sustaining Treatment Training Center: [www.compassionandsupport.org/index.php/for\\_professionals/molst\\_training\\_center](http://www.compassionandsupport.org/index.php/for_professionals/molst_training_center)
- VitalTalk: [www.vitaltalk.org](http://www.vitaltalk.org)  
*Topics include Talking About Dying, Transitions/Goals of Care, Family Conference, Discussing Prognosis, Serious News, and Do Not Resuscitate Orders. The VitalTalk app in iTunes offers just-in-time supports before challenging conversations.*
- Aging With Dignity. Five Wishes Conversation Guide for Physicians: [www.agingwithdignity.org/shop/product-details/the-conversation-guide-for-physicians](http://www.agingwithdignity.org/shop/product-details/the-conversation-guide-for-physicians) (for purchase)

### Reimbursement for Advance Care Planning

- Centers for Medicare & Medicaid Services. Frequently Asked Questions About Billing the Physician Fee Schedule for Advance Care Planning Services: [www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/PhysicianFeeSched/Downloads/FAQ-Advance-Care-Planning.pdf](http://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/PhysicianFeeSched/Downloads/FAQ-Advance-Care-Planning.pdf)

## RESOURCES FOR PATIENTS

### Care Planning Tools

- PREPARE: [www.prepareforyourcare.org](http://www.prepareforyourcare.org) (no cost)  
*Videos and stories to teach people how to identify their medical care goals*
- ACP: [www.acpdecisions.org/patients](http://www.acpdecisions.org/patients) (no cost)  
*Advance care planning tool*
- Aging With Dignity: [www.agingwithdignity.org/five-wishes/individuals-and-families](http://www.agingwithdignity.org/five-wishes/individuals-and-families)  
*Advance care planning tool*

### New York State Forms

- NYS Health Care Proxy form: [www.health.ny.gov/publications/1430.pdf](http://www.health.ny.gov/publications/1430.pdf)
- NYS Living Will form: [www.compassionandsupport.org/pdfs/research/Living\\_Will\\_Form.pdf](http://www.compassionandsupport.org/pdfs/research/Living_Will_Form.pdf)

### Palliative Care Services Locator

- Center to Advance Palliative Care site for patients and families: [getpalliativecare.org/](http://getpalliativecare.org/)

### Hospice Services Locator

- Hospice and Palliative Care Association of New York State: [www.hpcanys.org/find-care/](http://www.hpcanys.org/find-care/)

### Support Groups

- American Cancer Society: [www.cancer.org](http://www.cancer.org); 800-227-2345
- American Lung Association: [www.lung.org](http://www.lung.org); 800-LUNG-USA (800-586-4872)
- National Kidney Foundation: [www.kidney.org](http://www.kidney.org); 855-NKF-CARES (855-653-2273)
- American Heart Association New York City Homepage: [www.heart.org/HEARTORG/Affiliate/Welcome-to-the-New-York-City-Home-Page\\_UCM\\_FDA004\\_AffiliatePage.jsp](http://www.heart.org/HEARTORG/Affiliate/Welcome-to-the-New-York-City-Home-Page_UCM_FDA004_AffiliatePage.jsp); 212-878-5900
- Alzheimer's Association: [www.alz.org](http://www.alz.org); 800-272-3900
- Healthfinder.gov: [healthfinder.gov/FindServices/SearchContext.aspx?topic=833](http://healthfinder.gov/FindServices/SearchContext.aspx?topic=833)  
*Support resources for a variety of illnesses*

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**Consultants:** Diane E. Meier, MD, Director, Center to Advance Palliative Care, Vice Chair for Public Policy and Professor, Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai; R. Sean Morrison, MD, Director, Hertzberg Palliative Care Institute, Icahn School of Medicine at Mount Sinai

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E-mail *City Health Information* at: [nycdohrp@health.nyc.gov](mailto:nycdohrp@health.nyc.gov)

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