

City Health Information

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The New York City Department of Health and Mental Hygiene

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IMPROVING PALLIATIVE CARE AT THE END OF LIFE

- Provide advance care planning for all patients and document their wishes in advance directives.
- Manage pain and other symptoms to ensure the highest possible quality of life for patients with serious or terminal illnesses.
- Refer patients to specialized palliative care teams or hospice when appropriate.

ew Yorkers are living longer than ever and, as in the rest of the nation, the size of the older population is increasing. The nature of serious illness and death has changed: instead of rapid, acute episodes leading to death, more people experience a gradual decline due to one or more chronic illnesses.² During a serious illness or as they approach the end of life, patients may prefer treatments that manage symptoms and preserve quality of life over more aggressive approaches.3 Physicians can assist patients in setting personal treatment and care goals and help ensure that endof-life care is delivered according to patients' wishes if they become incapacitated.4 Without advance care planning, patients might receive aggressive medical care they do not want, increasing physical and psychological stress.5 Physicians should be knowledgeable about palliative and hospice care, which emphasize symptom management and quality of life for patients with advanced illness.

ADVANCE CARE PLANNING

Advance care planning is the process of planning for future medical care in case a patient is unable to make decisions. Advance care planning is important to everyone and should be discussed with all adult patients, particularly those facing serious illness. These discussions encourage patients to consider future circumstances, formulate preferences about end-of-life care, and identify a relative or friend who can serve as their health care agent.⁴ Advance care planning is also associated

with increased hospice referrals and less aggressive medical care at the end of life.⁵

Two legal documents should be discussed; together, they form the patient's advance directive.⁴

- **Health Care Proxy:** a standard form approved under New York State (NYS) law. Patients use this form to designate an agent who can make decisions with the medical team if a physician determines that the patient is not able to participate in decision-making (**Resources**).
- Living Will or Medical Directive: a written declaration that provides clear and convincing evidence of a patient's health care wishes. This can take the form of a personal letter, a statement, or a worksheet (Resources).



REIMBURSEMENT FOR ADVANCE CARE PLANNING

Advance care planning (which can encompass counseling and coordination of care) is usually reimbursable using appropriate Current Procedural Terminology (CPT) codes. Information and CPT codes can be found at:

www.aahpm.org/physresources/coding.html#Physician.

These documents work together: the proxy designation authorizes an agent to make decisions about treatment, and the living will provides guidance to the agent, health care professionals, and institutions about the patient's health care wishes.⁴

To help a patient identify a potential health care agent, you might ask:^{6,7}

- If you were seriously injured tomorrow, who would you trust to help me and other doctors make medical decisions on your behalf?
- Would you prefer a family member? Your agent does not have to be a member of your family.
 You can also name an alternate should the primary agent be unavailable.
- Have you discussed these issues with the people you trust? Let them know that you would like them to act on your behalf should it ever become necessary.

There are several worksheets to help patients decide on care preferences. Once those decisions are recorded, a clinician can make them part of the patient's medical record; the patient can also use the worksheet as the living will or to inform completion of a standard living will form (**Resources**).⁴

Many physicians find that being involved in the advance care planning process helps to build trust and aids subsequent decision-making. Alternatively, another team member (e.g., nurse practitioner) can introduce the topic and help patients fill out a worksheet. Patients can then discuss their wishes with family members and identify a health care agent prior to the next physician visit.⁷

Clinicians and agents should be comfortable honoring the patient's preferences; if not, discuss the patient's decisions until all are comfortable. Review and update a patient's advance directive periodically and when there is a major life change (such as marriage, birth, death, divorce) or significant change in health status. Revise the documents contained in the patient's medical record and in the possession of the health care agent.⁴

If a patient has a terminal or advanced illness, you might also discuss the **Medical Orders for Life-Sustaining Treatment** (MOLST) form (see box, page 3), which converts the patient's preferences for receiving life-sustaining treatments into medical orders that are effective immediately—before the patient is incapacitated. Patients can also fill out a NYS Durable Power of Attorney form (**Resources**) to designate a

APPOINTING A HEALTH CARE AGENT IN NEW YORK STATE

Under New York State (NYS) law, patients may choose any adult 18 years of age or older, including a family member or close friend, to be a health care agent. In NYS, only an appointed health care agent has the legal authority to make treatment decisions if a person is temporarily unable to do so (e.g., coma after an accident). Once the patient regains decision-making capability, the agent is no longer authorized to act. In case of permanent inability to make decisions (e.g., persistent vegetative state), all appropriate medical treatments are provided to the patient unless an agent has been appointed to make treatment decisions in accordance with the patient's wishes (which can be detailed in a living will). Everyone over the age of 18 needs a health care agent.

NYS law specifically requires patients to fill out a health care proxy form to appoint their health care agent; hospitals and other health care facilities are required to provide information and proxy forms. A living will cannot be used to name a health care agent. Information and health proxy forms can be found at: www.health.state.ny.us/professionals/patients/health_care_proxy/instructions.htm.

Proxy forms can also be obtained by calling 311.

MEDICAL ORDERS FOR LIFE-SUSTAINING TREATMENT (MOLST)⁸

Medical Orders for Life-Sustaining Treatment (MOLST) is a New York State-approved form that converts the end-of-life care preferences of a seriously ill patient into formal medical orders regarding life-sustaining treatments such as resuscitation (CPR), intubation, medication, or artificial nutrition, and whether the patient wishes to be taken to a hospital. The form is designed to travel with the patient across health care settings and is easily identified by its bright pink color (faxes and photocopies are also acceptable and legal). A completed MOLST form carries the same weight as an in-hospital Do Not Resuscitate (DNR) or Do Not Intubate (DNI) order.

The MOLST form is filled out by a health care professional after discussion with the patient, and must be signed by a NYS-licensed physician.

Because it is designed for immediate use and reflects a patient's current preferences and medical situation, the MOLST form must be reviewed and renewed by a physician at least every 7 days

in hospitals, every 60 days in nursing homes, and

The MOLST form does not take the place of an advance directive and is not conditional on loss of decision-making capacity.

every 90 days in other community settings.

For information, see:

www.health.state.ny.us/professionals/patients/patient_rights/molst/frequently_asked_questions.htm.

person to make property, financial, and other legal non-health-care decisions on their behalf.⁴

WHAT IS PALLIATIVE CARE?

Palliative care focuses on relieving pain and other distressing symptoms in the face of serious illness, and assures continuity, coordination, and care planning for patients entering the end stages of disease. Palliative care also addresses the spiritual and psychological needs of the patient and family. It can be provided at any time in the course of an illness in conjunction with curative treatments.^{3,9}

ESTABLISHING GOALS OF CARE

Treatment choices can depend on whether an illness is terminal or life-threatening but treatable and on a patient's personal goals. For example, someone facing the last days of life may want to live long enough with the best possible quality of life to participate in a graduation, a wedding, or the birth of a child. Functional limitations and personal experiences (such as having a relative with dementia) can also affect goals.^{3,10,11}

You can help patients establish care goals by discussing what is reasonable or possible in their specific circumstances. Care goals can change as an illness progresses, so they need to be reevaluated and updated regularly.^{3,11}

Questions to ask patients to help clarify care goals include:⁶

- What is most important for you in your life right now?
- What are your most important hopes?
- What do you hope to avoid most of all?

Ask patients which options they prefer:

- Attempt cure; use all appropriate interventions.
- Give curative treatments where appropriate and manage other conditions; avoid aggressive interventions.
- Keep me comfortable and emphasize quality of what time remains; avoid potentially lifeprolonging interventions.

SYMPTOM MANAGEMENT

Symptom management is essential to maintaining a patient's quality of life. The most common and burdensome symptom is pain.^{11,12}

Pain. Although pain is known as the "fifth vital sign," it is often poorly assessed and managed. The simplest means of assessing pain is to ask the patient to rate his or her pain on a scale of zero to 10, in which zero is no pain and 10 is the worst imaginable pain. Appropriately prescribed medication can be adjusted if pain reaches level 4 or higher on the pain scale.¹³

There are two types of pain, and each responds to different medications. *Nociceptive* (somatic or visceral) pain involves nociceptors (sensory neurons throughout the body) and can include cancer pain, joint and back

pain, headaches, and gastrointestinal distress. *Neuropathic* pain stems from disordered nervous system function and typically causes burning, tingling, or electric-like sensations. Normal historytaking can usually help determine the type of pain a patient is experiencing.

Nociceptive pain generally responds well to opioids and/or adjuvant medications. For neuropathic pain, certain adjuvant medications (e.g., tricyclic antidepressants, anticonvulsants) can be combined with opioids when needed (**Resources**). 13-15

The World Health Organization (WHO) 3-step ladder provides another simple, well-tested approach to pain management (**Figure 1**). Start management at the relevant severity level and step up as needed. It is essential to routinely monitor pain and symptoms—

<u>+</u> Adjuvants

which can vary according to a patient's condition—and adjust medication appropriately using validated pain assessment instruments (**Resources**).

A major barrier to effective pain management is concern about addiction and the safety of opioid medications. ^{13,14} Patients who need opioids to control chronic pain rarely become addicted if medications are correctly managed. Patients can develop physical dependence with a need for larger doses of medication and may experience withdrawal if opioid medications are withheld or tapered too quickly. However, opioid addiction—in which a person craves the drug despite its damaging effects and engages in harmful behaviors to secure the drug—is rare among patients who did not display such tendencies prior to their illness. ^{14,15}



Adjuvants = medications added to manage side effects or enhance analgesia, which include antidepressants, anticonvulsants, benzodiazepines, and anesthetics. Adapted from WHO Cancer Pain Relief: With a Guide to Opioid Availability. 2nd ed., 1996. Ferris FD, Von Gunten CF, Emanuel LL. Ensuring competency in end-of-life care: controlling symptoms. BMC Palliat Care. 2002;1(1):5.

Because abuse of prescription pain relievers is a large and growing problem,¹⁶ instruct your patients to store medications securely and not share them with others. Prescribe only amounts necessary for patients themselves and monitor refill requests to identify unexpectedly high use, which may indicate diversion to others.

Side effects of opioids include mental confusion, respiratory depression, and constipation. Mental confusion is dose related, so it is important to prescribe the lowest effective dose of the opioid. Respiratory depression usually occurs at opioid doses that are much higher than those needed to manage pain; it does not occur suddenly if the dose is escalated gradually. Constipation should be managed proactively with the use of fluids, dietary fiber, and stool softeners or laxatives. Ongoing assessment and appropriate titration of opioids based on pharmacologic principles can prevent problems; consider consultation with a pain management specialist if any difficulties or concerns arise (**Resources**).

Other common symptoms. Physical symptoms near the end of life can include breathlessness (dyspnea), nausea/vomiting, constipation, diarrhea, anorexia/cachexia, fatigue, fluid imbalance/edema, pressure ulcers, and insomnia. Common psychological symptoms include depression and anxiety. Delirium can also occur as terminal illness progresses.^{3,14} See **Resources** for more information on symptom management.

REFERRAL TO SPECIALIZED PALLIATIVE CARE AND HOSPICE SERVICES

Specialized palliative care. Many hospitals offer specialized palliative care programs that coordinate care across multiple sites and settings when patient and family needs can no longer be met solely by the primary care physician. Consultation with or referral to palliative care services can help reduce suffering and avoid unnecessary hospitalizations and emergency department (ED) visits. A list of hospital-based palliative care programs can be found at www.getpalliativecare.org/providers/.

MEDICARE HOSPICE BENEFITS17

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

- Eligible for Medicare Part A (Hospital Insurance).
- The 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 Medicarecovered benefits to treat the terminal illness.*
- Hospice care is provided by a Medicareapproved hospice program.

Medicare hospice benefits cover:

- Doctor services, nursing care.
- Physical, speech, and occupational therapy.
- Social worker services.
- Medical equipment and supplies.
- Drugs for symptom control or pain relief (small copayment).
- 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).
- Short-term respite care (small copayment).
- Any other Medicare-covered services needed to manage pain and other symptoms, as recommended by the hospice team.

It may be possible for you to continue to care for a patient receiving Medicare Hospice Benefits. To avoid reimbursement denials by insurance carriers and intermediaries, you must use different ICD-9-CM diagnosis codes from those being used by other clinicians seeing the patient on the same day. Appropriate documentation in the patient's medical record must always support the codes submitted. For information on coding, see www.aahpm.org/physresources/coding.html#Physician.

^{*}Medicare will continue to cover medical care not related to the terminal illness.

Hospice care. For patients in advanced stages of illness, hospice care can also reduce suffering and prevent unnecessary hospitalizations and ED visits. Hospice care focuses on symptom management and does *not* include curative treatment. Referral is appropriate when a patient has a limited life expectancy and no longer wishes life-prolonging procedures (e.g., intravenous feeding).^{3,11,17} Discuss hospice care with patients and families and encourage its use when it fits with patient care goals.

Hospice services are known to improve quality of life for patients and families,⁵ yet such services are vastly underutilized in NYS. In the period 2000-2003, only 19% of decedents were enrolled in hospice care in the last 6 months of life, compared with the national average of 27%.¹⁸

Underutilization may be due to misperceptions about hospice care. Patients often think hospice care is available only at specialized facilities and does not include medical treatment. In fact, hospice care is most often delivered at home and includes medical care and pain management, as well as emotional and spiritual support. To help patients and families better understand hospice care, use resources available from organizations such as the National Hospice and Palliative Care Organization (**Resources**). Asking specific questions of a hospice can help patients choose the hospice program best suited to their needs.¹⁹

SAMPLE QUESTIONS TO ASK THE HOSPICE

- What services are provided?
- Are physicians board certified in palliative medicine?
- How are services provided after hours?
- How and where does hospice provide short-term inpatient care?
- With which nursing homes or long-term care facilities does the hospice work?
- How long does it typically take the hospice to enroll someone once the request for services is made?

It is best for the patient and family if the primary care provider remains involved after referral to hospice care. However, many hospice programs have physicians who can make visits, provide consultations and expertise, and coordinate with the primary care provider (or take charge of the patient if that is the best option for all concerned). Further information on hospice programs can be found in **Resources**.

CULTURAL CONSIDERATIONS

Cultural competence is essential in all aspects of medical care. However, culture is especially important in death and dying, and often informs the meaning patients and families attach to the end of life and their expectations during this time. Considerations include:^{11,20}

Linguistic barriers and medical literacy. If there is a language barrier, try to use a professional interpreter rather than a family member; this helps to avoid role changes that may be uncomfortable for the family and ensures that communication is unfiltered. It is best to have the translator sit in a triangle with you and the patient so that you can face the patient. Take the time to assess how well a patient comprehends medical issues and use vocabulary and concepts that he or she can understand.

Alternative medical traditions. Remedies common to the patient's culture may provide important sources of comfort in an illness. Try to accommodate traditional remedies if they are not harmful.

Cultural values. Autonomy is important in mainstream American culture, but other ethnic groups may emphasize matriarchal or patriarchal roles and have different approaches to conveying medical information (truthtelling) and decision-making. Cultural approaches to dying can differ, with fatalism being more common in some cultures and fighting the inevitable more common in others. The meaning of suffering can also vary dramatically; therefore, coping mechanisms that can be addressed by the physician will vary as well. Often the best approach is to simply ask whether the patient holds a belief that is prevalent within a culture, rather than making an assumption. You may say something like:

- How do you like to handle important information about your medical care?
- What helps you in this kind of situation?

RESOURCES

Continuing Medical Education/Certificate Granting Programs

- Education in Palliative and End-of-life Care (EPEC™)
 Project. Online CME modules for purchase at:
 www.epec.net
- End-of-Life Nursing Education Consortium (ELNEC)
 Core Curriculum for Nurses:
 www.aacn.nche.edu/ELNEC/curriculum.htm
- Center to Advance Palliative Care (CAPC). Instructions on how to set up palliative care programs: www.capc.org/

Advance Directive Worksheets

- Advance Care Planning for NY Residents: www.compassionandsupport.org/index.php/ resource_directory/advance_care_planning
- New York State Department of Health. Planning Your Health Care in Advance: How to Make Your End-of-Life Wishes Known and Honored: www.oag.state.ny.us/bureaus/health_care/ pdfs/EOLGUIDE012605.pdf
- Center for Practical Bioethics. Caring Conversations: www.practicalbioethics.org/fileuploads/Caring%20C onversations.121406.pdf
- Your Life, Your Choices: www.rihlp.org/pubs/Your_life_your_choices.pdf
- The Medical Directive (available for purchase): www.medicaldirective.org
- Aging With Dignity: The Five Wishes (available for purchase): www.agingwithdignity.org/5wishes.pdf
- New York City Department of Health and Mental Hygiene NYC DOHMH Health Bulletin #67: Who will make your medical decisions if you can't? www.nyc.gov/html/doh/downloads/pdf/public/dohmh news7-12.pdf

Forms

- NYS Health Care Proxy form: www.health.state.ny.us/forms/doh-1430.pdf
- NYS Health Care Proxy order form for multiple copies: www.nyhealth.gov/forms/order_forms/health_ care_proxy.pdf or call 311 and ask for Health Care Proxy forms
- NYS Living Will form: www.compassionandsupport.org/pdfs/research/ Living_Will_Form.pdf
- NYS Durable Power of Attorney Statutory Short Form: www.nylawfund.org/pubs/durpoa.pdf

MOLST forms:

www.excellusbcbs.com/wps/portal/xl

MOLST Training Center:

www.compassionandsupport.org/index.php/for_professionals/molst_training_center

U.S. Living Will Registry:
 www.uslivingwillregistry.com/register.shtm

Symptom Management

- Pain Management Resource Directory (includes assessment tools):
 - www.compassionandsupport.org/index.php/for_professionals/pain_management
- City of Hope Professional Resource Center (includes assessment tools): http://prc.coh.org
- American Medical Association: Pain management: the online series (includes assessment tools): www.ama-cmeonline.com/pain_mgmt
- The End of Life/Palliative Education Resource Center (EPERC), Fast Facts Index: www.eperc.mcw.edu/ff_index.htm

Pain Medicine and Palliative Care Specialists

- The Hospice and Palliative Care Association of New York State:
 - http://www.hpcanys.org/find_palliative.asp
- Palliative Care Provider Directory of Hospitals: www.getpalliativecare.org/providers/
- American Academy of Pain Medicine: www.painmed.org

Hospice Programs

- National Association for Home Care and Hospice, hospice locator: www.nahc.org/AgencyLocator/
- National Hospice and Palliative Care Organization: www.nhpco.org/i4a/pages/index.cfm?pageid=3254
- American Hospice Foundation: www.americanhospice.org
- Hospice Resource Directory: www.compassionandsupport.org/index.php/ resource directory/hospice
- Centers for Medicare and Medicaid Services. Medicare Hospice Benefits:

www.medicare.gov/publications/pubs/pdf/02154.pdf

Reimbursement

 American Academy of Hospice and Palliative Medicine: www.aahpm.org/physresources/coding.html#Physician (Continued from page 6)

Meaning and ritual. Meanings attributed to food, caretaking, illness, and dying vary markedly among cultures. Rituals triggered by stages of illness or death are different among and within traditions. Again, it is best to ask patients and families about what is meaningful to them. Questions may include:

- What do you normally do in this situation?
- Are there rituals I can help arrange for you?
- It is hard when a person can't eat normal foods any more. What does food mean to you? Let's try to find a way to express the meaning of this food in some other way.

FAMILY CAREGIVER SUPPORT

Family caregivers are usually under considerable stress and may neglect their own health.²¹ Ask how caregivers are doing, and recommend support services such as

respite care (available through many palliative and hospice care programs), which allows caregivers to take time for themselves to avoid burnout and depression.²²

SUMMARY

Advance care planning can make medical decision-making and patient care easier while ensuring that a patient's care preferences will be honored if he or she is unable to make decisions. Palliative care, which focuses on alleviating pain and addressing the spiritual and psychological needs of seriously ill patients and their families, can be provided at any time in conjunction with curative treatment. Hospice care also focuses on pain relief and emotional and spiritual support, but is intended for patients who have a limited life expectancy and no longer wish aggressive medical treatment. Understanding and utilizing these options helps ensure quality of life at the end of life. •

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Continuing Education Activity

Improving Palliative Care at the End of Life

SPONSORED BY THE NEW YORK CITY DEPARTMENT OF

HEALTH AND MENTAL HYGIENE (DOHMH) CITY HEALTH INFORMATION JANUARY/FEBRUARY 2009 VOL. 28(1):1-8

Objectives

At the conclusion of this activity, participants should:

- 1. Understand the components of palliative care. 2. Understand pain and symptom management.
- including use of appropriate medications. 3. Be able to explain the components of advance care
- planning to patients and families. 4. Understand appropriate referral to specialized palliative care teams and hospice.

CME Accreditation Statement

The New York City Department of Health and Mental Hygiene is accredited by the Medical Society of the State of New York to sponsor continuing medical education for physicians. The New York City Department of Health and Mental Hygiene designates this continuing medical education activity for a maximum of 1.5 AMA PRA Category 1 credit(s).TM Each physician should only claim credit commensurate with the extent of their participation in the activity.

CNE Accreditation Statement The New York City Department of Health and Mental Hygiene is an approved provider of continuing nursing education by the New York State Nurses Association,

an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.

This CNE activity has been awarded 1.5 contact hours. It has been assigned code 6WXLFX-PRV-079.

Participants are required to submit name, address, and professional degree. This information will be maintained in the Department's CME/CNE program database. If you request, the CME/CNE Program will verify your participation and whether you passed the exam. We will not share information with other organizations

without your permission, except in certain emergencies

deemed by the public health agencies to be essential or when required by law. Participants who provide e-mail addresses may receive electronic announcements from the Department about future CME/CNE activities as well as other public health information.

when communication with health care providers is

Participants must submit the accompanying exam by February 29, 2012.

CME/CNE Activity Faculty: Linda L. Emanuel, MD. PhD

Erica Desai, MPA

Louise Cohen, MPH

E. Desai and L. Cohen are affiliated with New York City DOHMH: Dr. Emanuel is affiliated with Northwestern University. The faculty does not have any financial arrangements or affiliations with any commercial entities whose products, research, or

services may be discussed in these materials.

CME/CNE Activity Improving Palligtive Care at the End of Life 1. Which of the following is NOT true regarding

palliative care?					
		Α.	It involves expert communication	about the	goal:

- ls of care. ☐ B. Key components are coordination and care planning for
- patients at end stages of disease. C. It addresses the spiritual and psychological needs of the
- patient and family. D. It can only be provided when curative treatment is no longer an option.

2. A health care proxy is:

- ☐ A. A plan for future medical care in case a patient is incapacitated or unable to make decisions.
- ☐ B. A legal document appointing an agent who will work with the patient's medical team to make health care decisions when a physician determines the patient is not able to
- participate in decision-making. C. Written instructions about a patient's health care wishes. D. The process of planning for future medical care in case a
- patient is incapacitated or unable to make decisions.

3. Which of the following is NOT true regarding pain management in patients near the end of life? A. Although pain is known as the "fifth vital sign," it is often

- poorly managed. ☐ B. Opioid addiction is rare in patients who did not display
- such tendencies prior to their illness. C. On a scale of zero to 10, in which zero is pain free and 10 is the worst imaginable pain, medication should be
- adjusted only if the pain reaches level 7 or higher. D. Side effects of opioids include confusion, constipation, and respiratory depression.

A. Anorexia an	d cachexia.	
□ B. Anxiety and	depression.	
□ C. Constipation	i.	
D. Dyspnea.		
□ E. Nausea/vor	niting.	
☐ F. All of the about	ove.	
. How well did th	is continuing educat	ion activity
achieve its educe	ational objectives?	-
A. Very well.	B. Adequately.	C. Poorly.
. Will the content	learned from this ac	tivity impact
your practice?		

□ B. No.

4. Common non-pain symptoms for patients at the end

January/February 2009

C. Not applicable.

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□ A. Yes.

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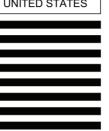


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