

# Palliative Care, Hospice and Relevant Laws

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# Palliative Care

A definition of palliative care by the Center to Advance Palliative Care:

- “Palliative care is specialized health care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family.

# Palliative Care

- Provided by a specially-trained team, palliative care specialists work together with a patient's other doctors to provide an extra layer of support. Palliative care is based on the needs of the patient, not on the patient's prognosis. It is appropriate at any age and at any point in a serious illness and can be delivered with curative treatment.”

# Palliative Care

Addresses:

Physical symptoms, pain, nausea, breathlessness, fatigue, constipation, loss of appetite, etc.

Anxiety and depression

Psycho-social issues

Spiritual issues

Can also address legal and other difficult issues

# Palliative Care

Center to Advance Palliative Care 2011 Survey found:

- 70% of public was “not at all knowledgeable” about palliative care;
- A recent 2018 survey in Journal of Palliative Medicine found that an estimated 71% of US adults had never heard of palliative care.
- Once informed about palliative care 95% agreed it was important that patients with serious illness, as well as families, be educated about palliative care;

# Palliative Care

- 92% said they would be likely to consider palliative care for a loved one if they had a serious illness;
- 92% said it is important that palliative care services be made available at all hospitals for patients with serious illness and their families.
- “Physicians tend to either equate palliative care with “hospice” or “end of life” care and they are very resistant to believing otherwise.”

# Palliative Care

Barriers to the provision of palliative care might include:

- Doctors and other healthcare professionals not knowing that palliative care is provided at the hospital.
- Doctors and other health care professionals not understanding what palliative care is and the difference between it and hospice.

# Palliative Care

- Unwillingness of doctors and other health care professionals to refer appropriate patients either at all or in a timely fashion.
- Not enough palliative care professionals; there are only about 7,600 physicians who are board certified in palliative care nationwide



# Palliative Care

- **Are there differences between palliative care and hospice?**
- Yes, palliative care is appropriately offered at any time during a serious illness. It is not limited to end-of-life care.
- One difference between palliative care and hospice care is that hospice care is a formal system of care specific to end of life care and is provided by certified hospice agencies.

# Palliative Care

- Palliative care is delivered throughout the course of an illness along with curative or life-prolonging care regardless of prognosis.
- Palliative care is therefore provided by many different types of providers in various settings including: hospitals, nursing homes, home health agencies, and concludes with hospice care when life expectancy is limited.

# Palliative Care

- Patients and providers should recognize that palliative care and disease-modifying therapies are not mutually exclusive.
- Patients may opt to pursue palliative care while also pursuing aggressive treatment.
- Palliative care may be provided together with life-prolonging or curative care as the main focus of care.

# Palliative Care

- Patients may not get palliative care either at all or timely unless they or advocates for them ask for it.
- If you think you or a patient you work with can benefit from palliative care, do not hesitate to request it.

# Palliative Care

In New York we have a law re the provision of palliative care:

- Palliative Care Access Act (PCAA) effective September, 2011:  
Public Health Law, Section 2997-d
- Applies to hospitals, nursing homes, home care agencies and enhanced and special needs assisted living residences.

# Palliative Care

- Applies to patients with advanced, life limiting conditions and illnesses who might benefit from palliative care.
- Requires providers to establish policies and procedures to provide these patients:
- Services with access to information and counseling concerning palliative care and pain management appropriate to the patient, and

# Palliative Care

- Facilitate access to appropriate palliative care and pain management consultations and services
- Provide the information and counseling to those lawfully authorized to make decisions for patients who lack capacity to make medical decisions.

# Palliative Care

According to the NYS Department of Health,

- “, the PCAA is intended to ensure that patients are fully informed of the options available to them when they are faced with a serious illness or condition, so that they are empowered to make choices consistent with their goals of care, and wishes and beliefs, and to optimize their quality of life.



# Palliative Care

The Palliative Care Information Act, Public Health Law, Section 2997-c, requires that:

- If a patient is diagnosed with a terminal illness or condition, the patient's attending health care practitioner must offer to provide the patient with information and counseling regarding palliative care and end-of-life options appropriate to the patient and information regarding other appropriate treatment options should the patient wish to initiate or continue treatment.

# Palliative Care

- “Palliative Care:” 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.
- “Terminal Illness or Condition:” Reasonably expected to cause death within 6 months.

# Palliative Care

Information and counseling offered shall include but not be limited to:

- The range of options appropriate to the patient;
- Prognosis;
- Risks and benefits of the various options;
- Patient's legal rights to comprehensive pain and symptom management at the end of life;
- May be provided orally or in writing;
- If patient lacks capacity, information and counseling is to be provided to the health care agent or surrogate.

# Palliative Care

For some dying patients the following options might be appropriate:

- Voluntarily Stopping Eating and Drinking (VSED)—Information might be provided to patients about their right to stop eating and drinking when palliative care does not relieve suffering that the terminally ill patient finds intolerable.
- Palliative Sedation— Information about palliative sedation to unconsciousness, when other efforts to control symptoms and relieve suffering have been unsuccessful, might also be provided to dying patients. ( AMA, 2008 and NHPCO, 2010 Statements)

# MOLST Form

NEW YORK STATE DEPARTMENT OF HEALTH

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

THE PATIENT KEEPS THE ORIGINAL MOLST FORM DURING TRAVEL TO DIFFERENT CARE SETTINGS. THE PHYSICIAN OR NURSE PRACTITIONER KEEPS A COPY.

LAST NAME, FIRST NAME, MIDDLE INITIAL OF PATIENT \_\_\_\_\_

ADDRESS \_\_\_\_\_

CITY/STATE/ZIP \_\_\_\_\_

DATE OF BIRTH (MM/DD/YYYY) \_\_\_\_\_  Male  Female  #MOLST NUMBER (THIS IS NOT AN #MOLST FORM) \_\_\_\_\_

### Do-Not-Resuscitate (DNR) and Other Life-Sustaining Treatment (LST)

This is a medical order form that tells others the patient's wishes for life-sustaining treatment. A health care professional must complete or change the MOLST form based on the patient's current medical condition, values, wishes, and MOLST Instructions. If the patient is unable to make medical decisions, the orders should reflect patient wishes, as best understood by the health care agent or surrogate. A physician or nurse practitioner must sign the MOLST form. All health care professionals must follow these medical orders as the patient moves from one location to another, unless a physician or nurse practitioner examines the patient, reviews the orders, and changes them.

MOLST is generally for patients with serious health conditions. The patient or other decision-maker should work with the physician or nurse practitioner and consider asking the physician or nurse practitioner to fill out a MOLST form if the patient:

- Wants to avoid or receive any or all life-sustaining treatment.
- Resides in a long-term care facility or requires long-term care services.
- Might die within the next year.

If the patient has an intellectual or developmental disability (I/DD) and lacks the capacity to decide, the doctor (not a nurse practitioner) must follow special procedures and attach the completed Office for People with Developmental Disabilities (OPWDD) legal requirements checklist before signing the MOLST. See page 4.

### SECTION A Resuscitation Instructions When the Patient Has No Pulse and/or Is Not Breathing

Check one:

- CPR Order: Attempt Cardio-Pulmonary Resuscitation**  
CPR involves artificial breathing and forceful pressure on the chest to try to restart the heart. It usually involves electric shock (defibrillation) and a plastic tube down the throat into the windpipe to assist breathing (intubation). It means that all medical treatments will be done to prolong life when the heart stops or breathing stops, including being placed on a breathing machine and being transferred to the hospital.
- DNR Order: Do Not Attempt Resuscitation (Allow Natural Death)**  
This means do not begin CPR, as defined above, to make the heart or breathing start again if either stops.

### SECTION B Consent for Resuscitation Instructions (Section A)

The patient can make a decision about resuscitation if he or she has the ability to decide about resuscitation. If the patient does NOT have the ability to decide about resuscitation and has a health care proxy, the health care agent makes this decision. If there is no health care proxy, another person will decide, chosen from a list based on NYS law. Individuals with I/DD who do not have capacity and do not have a health care proxy must follow SCPA 1750-b.

SIGNATURE \_\_\_\_\_  Check if verbal consent (Leave signature line blank) DATE/TIME \_\_\_\_\_

PRINT NAME OF DECISION MAKER \_\_\_\_\_

PRINT FIRST WITNESS NAME \_\_\_\_\_ PRINT SECOND WITNESS NAME \_\_\_\_\_  
Who made the decisions?  Patient  Health Care Agent  Public Health Law Surrogate  Minor's Parent/Guardian  §1750-b Surrogate\*

### SECTION C Physician or Nurse Practitioner Signature for Sections A and B

PHYSICIAN OR NURSE PRACTITIONER SIGNATURE\* \_\_\_\_\_ PRINT PHYSICIAN OR NURSE PRACTITIONER NAME \_\_\_\_\_ DATE/TIME \_\_\_\_\_

PHYSICIAN OR NURSE PRACTITIONER LICENSE NUMBER \_\_\_\_\_ PHYSICIAN OR NURSE PRACTITIONER PHONE/PAGER NUMBER \_\_\_\_\_

### SECTION D Advance Directives

Check all advance directives known to have been completed:

- Health Care Proxy  Living Will  Organ Donation  Documentation of Oral Advance Directive

\*If this decision is being made by a 1750-b surrogate, a physician must sign the MOLST.

THE PATIENT KEEPS THE ORIGINAL MOLST FORM DURING TRAVEL TO DIFFERENT CARE SETTINGS. THE PHYSICIAN OR NURSE PRACTITIONER KEEPS A COPY.

LAST NAME, FIRST NAME, MIDDLE INITIAL OF PATIENT \_\_\_\_\_ DATE OF BIRTH (MM/DD/YYYY) \_\_\_\_\_

### SECTION E Orders For Other Life-Sustaining Treatment and Future Hospitalization When the Patient has a Pulse and the Patient is Breathing

Life-sustaining treatment may be ordered for a trial period to determine if there is benefit to the patient. If a life-sustaining treatment is started, but turns out not to be helpful, the treatment can be stopped. Before stopping treatment, additional procedures may be needed as indicated on page 4.

**Treatment Guidelines** No matter what else is chosen, the patient will be treated with dignity and respect, and health care providers will offer comfort measures. *Check one:*

- Comfort measures only** Comfort measures are medical care and treatment provided with the primary goal of relieving pain and other symptoms and reducing suffering. Reasonable measures will be made to offer food and fluids by mouth. Medication, turning in bed, wound care and other measures will be used to relieve pain and suffering. Oxygen, suctioning and manual treatment of airway obstruction will be used as needed for comfort.
- Limited medical interventions** The patient will receive medication by mouth or through a vein, heart monitoring and all other necessary treatment, based on MOLST orders.
- No limitations on medical interventions** The patient will receive all needed treatments.

**Instructions for Intubation and Mechanical Ventilation** *Check one:*

- Do not intubate (DNI)** Do not place a tube down the patient's throat or connect to a breathing machine that pumps air into and out of lungs. Treatments are available for symptoms of shortness of breath, such as oxygen and morphine. (This box should not be checked if full CPR is checked in Section A.)
- A trial period** *Check one or both:*
- Intubation and mechanical ventilation**
  - Noninvasive ventilation (e.g. BiPAP), if the health care professional agrees that it is appropriate**
- Intubation and long-term mechanical ventilation, if needed** Place a tube down the patient's throat and connect to a breathing machine as long as it is medically needed.

**Future Hospitalization/Transfer** *Check one:*

- Do not send to the hospital unless pain or severe symptoms cannot be otherwise controlled.**
- Send to the hospital, if necessary, based on MOLST orders.**

**Artificially Administered Fluids and Nutrition** When a patient can no longer eat or drink, liquid food or fluids can be given by a tube inserted in the stomach or fluids can be given by a small plastic tube (catheter) inserted directly into the vein. If a patient chooses not to have either a feeding tube or IV fluids, food and fluids are offered as tolerated using careful hand feeding. **Additional procedures may be needed as indicated on page 4.**

*Check one each for feeding tube and IV fluids:*

- No feeding tube**  **No IV fluids**
- A trial period of feeding tube**  **A trial period of IV fluids**
- Long-term feeding tube, if needed**

**Antibiotics** *Check one:*

- Do not use antibiotics.** Use other comfort measures to relieve symptoms.
- Determine use or limitation of antibiotics when infection occurs.**
- Use antibiotics to treat infections, if medically indicated.**

**Other Instructions** about starting or stopping treatments discussed with the doctor or nurse practitioner or about other treatments not listed above (dialysis, transfusions, etc.).

**Consent for Life-Sustaining Treatment Orders (Section E)** (Same as Section B, which is the consent for Section A)

SIGNATURE \_\_\_\_\_  Check if verbal consent (Leave signature line blank) DATE/TIME \_\_\_\_\_

PRINT NAME OF DECISION MAKER \_\_\_\_\_

PRINT FIRST WITNESS NAME \_\_\_\_\_ PRINT SECOND WITNESS NAME \_\_\_\_\_

Who made the decisions?  Patient  Health Care Agent  Based on clear and convincing evidence of patient's wishes  Public Health Law Surrogate  Minor's Parent/Guardian  §1750-b Surrogate\*

**Physician or Nurse Practitioner Signature for Section E**

PHYSICIAN OR NURSE PRACTITIONER SIGNATURE\* \_\_\_\_\_ PRINT PHYSICIAN OR NURSE PRACTITIONER NAME \_\_\_\_\_ DATE/TIME \_\_\_\_\_

\*If this decision is being made by a 1750-b surrogate, a physician must sign the MOLST.

# Hospice

- Hospice is a system of care for individuals who have a life-limiting illness that is no longer responsive to curative treatment and life expectancy is approximately 6 months or less.
- Hospice is covered by most commercial insurance and is fully covered under the Medicare Hospice Benefit.

# Hospice

- Hospice care provides an interdisciplinary team of professionals and volunteers who are experts in end-of-life care, and focuses on symptom management needs and the quality of life of the patient.
- Hospice is not a specific place. Although hospice facilities or hospice homes may be in your community, hospice care is routinely provided at home, in nursing homes, and in hospitals.

# Hospice

## **What specific services does hospice provide?**

- Patient support and comfort including pain and other symptom control;
- Medical and social assessment;
- Nursing visits;
- Individual, family and group psycho-social and spiritual counseling;
- The provision of necessary equipment and supplies;
- Support for caregivers;



# Hospice

- Physical, occupational, speech or other types of therapy which might include pet or music therapy as appropriate;
- Dietary and nutritional advice;
- Homemaking and home health aide assistance; and
- Grief and bereavement support up to a year (or longer) for family members following the death of the patient.

# Hospice

- Hospice is not sufficiently utilized. Under 50% of dying patients nationwide and only about 30% in NY are enrolled in hospice at the end of life.
- And there are late referrals even when patients die in hospice; the vast majority die within a month and one third within a week.
- So, often terminally ill patients, loved ones or people advocating on their behalf, may have to ask for a hospice assessment by a doctor or hospice.

# Hospice

Steps to increase hospice utilization:

- Health care facilities and other institutions should have a policy in place like the Palliative Care Information Act requiring that information on end of life options including hospice be provided when a terminal diagnosis is made;
- Provide detailed information to dying patients and loved ones about the benefits of hospice and how it is a system of care to ensure a better quality of life while the patient continues to live until he or she dies.

# Hospice

- Explain that hospice is as much about living as about dying and remind loved ones that the patient is living until the last breath is taken.
- Explain that hospice does not mean giving up hope. The time when hospice care is appropriate is usually the time when hope turns from curative goals to goals of maintaining or having the best quality of life possible, time with family and loved ones, comfort care and finding dignity in each day.

# Hospice

- Dispel the many myths about hospice including those stated by the National Hospice and Palliative Care Organization in:
- COMMON MISCONCEPTIONS REGARDING HOSPICE
- **Hospice is where you go when there is nothing more a doctor can do.** Hospice is care designed for patients with a life-limiting illness.

# Hospice

- Hospice is not where you go to die, rather hospice professionals are trained to assist patients in living their lives fully, completely, and without pain until the end of their lives.
- **To be eligible for hospice, I have to be in the final stages of dying.** Hospice patients and families receive care for an unlimited amount of time, depending upon the course of the illness.

# Hospice

- There is no fixed limit on the amount of time a patient may continue to receive hospice services.
- **Quality care at the end of life is very expensive.** Medicare beneficiaries pay little or nothing for hospice. For those ineligible for Medicare, most insurance plans, HMO's, and managed care plans cover hospice care.

# Hospice

- **If I chose hospice care, I have to leave my home.** Hospice care is provided wherever the patient may be: in their own home or a family member's, a nursing home, or an assisted living facility. Hospice is also provided in in-patient units, VA Hospitals, and some correctional facilities.



# Hospice

- **Families are not able to care for people with life limiting illnesses.** Family members are encouraged, supported, and trained by hospice professionals to care for their loved ones. Hospice staff is on call to the patient and their families 24 hours a day, 7 days a week, to help family and friends care for their loved ones.

# Hospice

- **Hospice care is only for cancer or AIDS patients.** Fifty percent of hospice patients are diagnosed with conditions other than cancer or AIDS.
- **Hospice is just for the elderly.** Hospice is for anyone facing a life-limiting illness, regardless of age.

# Hospice

- **After the patient's death, hospice care ends.** Bereavement services and grief support are available to family members for up to one year after the death of a patient.

# Conclusion

- We can help at End of Life Choices New York.
- We have a counseling service provided, without charge, by Clinical Director, Judy Schwarz, a PhD nurse. She can be reached at [Judy@endoflifechoicesny.org](mailto:Judy@endoflifechoicesny.org), 212 252 2015
- Please contact Judy if you think she might be helpful on any of the issues discussed today.