Honoring Patient Preferences: The Role of MOLST

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A nonprofit independent licensee of the BlueCross BlueShield Association

New York State Ombudsmen, Fall 2006
Objectives

- Define role of MOLST in Advance Care Planning
- Describe appropriate use of MOLST
- Discuss MOLST as a POLST Paradigm
- Explain 8-Step MOLST Protocol
- Describe the MOLST Community Pilot in Monroe and Onondaga Counties
- Review available resources
Story with a Positive Outcome

- Advance Care Planning occurs
- Appropriate preparation for discussion
- Antecedent conversation occurs with physician and within family
- Goals guide care
- Documents exist, are regularly updated and are available
Difficult Clinical Stories

- Agent/Family disagree with physician assessment
- Agent/Physician agree while another family disagrees and interferes
- Agent/Family desire focus on QOL and physician disagrees
- Disagreement among physicians
- No agent/family; patient lacks capacity
Advance Care Directives

**For All Adults**

- Health Care Proxy Form
- Living Will
- Organ Donation (optional)

**For Those Who Are Chronically Ill or Near the End of Their Lives**

- Nonhospital Do Not Resuscitate (DNR) Order
- Medical Orders for Life Sustaining Treatment (MOLST) form
Health Care Proxy / Living Will & MOLST

Health Care Proxy / Living Will
- completed ahead of time
- applies only when decision-making capacity is lost

MOLST
- applies right now
- not conditional on losing decision-making capacity
- set of actionable medical orders
- approved by NYSDOH for use in hospitals and long-term care facilities
Advance Care Planning

Compassion, Support and Education along the Continuum

Advancing chronic illness

Chronic disease or functional decline
Multiple co-morbidities, with increasing frailty

Healthy and independent
Maintain & maximize health and independence
Death with dignity
Advance Care Planning

- Appropriate for all adults, not just the subset with life-limiting illness
- Process of planning for future medical care if you lose decisional capacity
- Focuses on conversation and addresses surrogate decision-making and end-of-life preferences
- Process results in the completion and use of legal documents
Advance Care Planning

- Reflect ongoing conversation with periodic reassessment and as needed
- Legal documents must be accessible
- Legal documents are helpful in preventing situations illustrated by Karen Ann Quinlan, Nancy Cruzan and Terri Schiavo
- Decreases turmoil and suffering and eases the burden for families of persons with life-limiting illness
Community-wide End-of-life/ Palliative Care Initiative

Advance Care Planning
- Community Conversations on Compassionate Care

Honoring Preferences
- Medical Orders for Life-Sustaining Treatment (MOLST)

Pain Management and Palliative Care
- Community Principles of Pain Management
- CompassionNet

Education and Communication
- Education for Physicians on End-of-life Care (EPEC)
- Community web site: www.compassionandsupport.org
Site of Death

How Americans Die

How Americans Wish to Die
### Site of Death:
#### National and State Data

<table>
<thead>
<tr>
<th></th>
<th>Deaths at home</th>
<th>Deaths in a Hospital</th>
<th>Deaths in a NH</th>
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<tbody>
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<td>Oregon (Nat'l Benchmark)</td>
<td>35.10%</td>
<td>32.50%</td>
<td>32.40%</td>
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<tr>
<td>National Mean (Average)</td>
<td>24.90%</td>
<td>50.00%</td>
<td>25.10%</td>
</tr>
<tr>
<td>New York</td>
<td>21.20%</td>
<td>61.80%</td>
<td>17.00%</td>
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</table>
Philosophy of POLST

- Individuals have the right to make their own health care decisions

- These rights include:
  - Making decisions about life sustaining treatment
  - Describing desires for life sustaining treatment to health care providers
  - Comfort care while having wishes honored
A decade of research in Oregon has proven that the POLST Program more accurately conveys end-of-life preferences and yields higher adherence by medical professionals.

Lee, Brummel-Smith, et al. JAGS. 2000; 48(10): 1219-1225
Schmidt, Hickman, Tolle, Brooks. JAGS. 2004; 52(9): 1430-1434
The POLST Program has been a key vehicle in Oregon’s successful efforts to increase the effectiveness of advance care planning and decrease unwanted hospitalizations at the end of life.

POLST is Spreading

National POLST Paradigm Initiative

Paradigm of communication, documentation, and system responsiveness
MOLST

- Created by the Community-wide End-of-Life/Palliative Care Initiative - November 2003
- Adapted from Oregon’s POLST
- Combines DNR, DNI, and other Life-Sustaining Treatments
- Revised October 2005
- Incorporates NYS law

www.compassionandsupport.org
Goals of the MOLST Program

• Document an individual’s treatment preferences:
  – DNR
  – Intubation and mechanical ventilation
  – Other life-sustaining treatment
  – Future hospitalization and transfer

• Coordinate physician orders with patient preferences

• Communicate wishes across health care settings

• Improve EMS personnel’s ability to treat according to patient wishes

• Reduce repetitive documentation
Core Elements of MOLST

- Contains actionable medical orders
- Recommended for use in persons who have advanced chronic progressive illness and anyone interested in further defining their end of life care wishes
- May be used either to limit medical interventions or to clarify a request for all medically indicated treatments including resuscitation
Core Elements of MOLST

- Provides explicit direction about resuscitation status if the patient is pulseless and apneic.
- Includes directions about other types of intervention that the patient may or may not want.
- Is a bright pink color that is easily identifiable in case of emergency.
Core Elements of MOLST

• Accompanies the patient and orders apply as he or she is transferred home or to a new care setting (e.g. long-term care facility or hospital).

• Should be reviewed and renewed:
  – Periodically
  – As required by NYS and federal law & regulations
  – If the individual’s preferences change
  – If the individual’s health status changes
  – If the patient is transferred to another care setting
Core Elements of MOLST

- Includes training of health care professionals about the goals of the program and use of the form
- Features a plan for ongoing monitoring of the program and its implementation
Pre-Hospital & Acute Care

LTC

Office

MOLST
MOLST: Who Should Have One?

- Anyone choosing:
  - Allow, embrace natural death
  - Do not resuscitate
- Anyone choosing to limit medical interventions
- Anyone eligible/residing in LTC facility
- Anyone who might die within the next year
Page 1: DNR
- Complete Section A, B, C for DNR
- Section D: Advance Directives

Page 2: Life-Sustaining Treatment

Page 3 and 4: Renew/Review Section

Supplemental Documentation Forms for DNR: Adult and Minor

www.compassionandsupport.org
• A paradigm shift for EMS
• Comfort Measures Only:
  – The patient is treated with dignity and respect. Reasonable measures are made to offer food and fluids by mouth. Medication, positioning, wound care, and other measures are used to relieve pain and suffering. Oxygen, suction and manual treatment of airway obstruction are used as needed for comfort.
Comfort Measures Only

• *Do Not Transfer* to hospital for life-sustaining treatment.

• *Transfer* if comfort care needs cannot be met in current location.
How to Complete a MOLST

- Must be completed by a health care professional, based on patient preferences
- Must be signed by a NYS licensed physician to be valid
- Verbal orders are acceptable with follow-up signature by a physician, in accordance with facility/community policy
How to Complete a MOLST

• The original form should remain in the patient’s possession
  – Readily identifiable pink color easier to locate in emergency

• Photocopies and faxes of signed MOLST forms are legal and valid

• Completion of the entire form is strongly recommended
  – Any section not completed implies full treatment
How to Complete a MOLST

• Consent for DNR must be obtained and documented in Section B of page 1
  – Individual with capacity can provide consent
  – Individual lacks capacity and designated Agent in Health Care Proxy, Agent can provide consent
  – Individual lacks capacity and without Agent, surrogate:
    • Designated health care agent
    • Court-appointed committee or guardian
    • Spouse
    • Son or daughter, age 18 or older
    • Parent
    • Brother or sister, age 18 or older
    • Close friend or person, age 18 or older
    • no appropriate surrogate decision-maker available
How to Complete a MOLST

• Authorization for ‘Orders for Life-Sustaining Treatment and Future Hospitalization’
  – Individual with capacity can provide consent
  – Individual lacks capacity, has designated Agent in Health Care Proxy: Agent can provide consent
  – Individual lacks capacity and without Agent: “clear and convincing evidence” of the individual’s preferences is required
    • Living will
    • Repeated oral expression
“There’s no easy way I can tell you this, so I’m sending you to someone who can.”
“The message behind the term ‘do not resuscitate’ is predominantly negative, suggesting an absence of treatment and care. The reality is that comfort care and palliative care are affirmative and, for these patients, more appropriate interventions”.

8-Step Protocol

1. Prepare for discussion
   – Understand the patient and family
   – Understand the patient’s condition and prognosis
   – Retrieve completed Advance Care Directives
   – Determine “Agent” (Spokesperson) or responsible party

2. Determine what the patient and family know
   – re: condition, prognosis

3. Explore goals, hopes and expectations

*Developed for NYS MOLST, Bomba, 2005*
8-Step Protocol

4. Suggest realistic goals
5. Respond empathetically
6. Use MOLST to guide choices and have patient/family share wishes
   – Shared medical decision making
   – Conflict resolution
7. Complete and sign MOLST
8. Review and revise periodically

Developed for NYS MOLST, Bomba, 2005
Shared Medical Decision Making

• Will treatment make a difference?

• Do burdens of treatment outweigh benefits?

• Is there hope of recovery?
  – If so, what will life be like afterward?

• What does the patient value?
  – What is the goal of care?
Potential Goals of Care

- Cure of disease
- Avoidance of premature death
- Maintenance or improvement in function
- Prolongation of life
- Relief of suffering
- Quality of life
- Staying in control
- A good death
- Support for families and loved ones
Multiple Goals of Care

- Multiple goals often apply simultaneously
- Goals are often contradictory
- Goals are sometimes unrealistic
- Certain goals may take priority over others
Goals May Change

- Some take precedence over others
- Gradual shift in focus of care
- Expected part of the continuum of medical care
When to Review and Renew

- Physician should review and renew MOLST
  - Periodically
  - If the individual’s preferences change
  - If the individual’s health status changes
  - If the patient is transferred to another care setting
- Physician must review and renew DNR order
  - Hospital: at least every 7 days
  - Nursing home/SNF: at least every 60 days
  - Nonhospital/community setting: at least every 90 days
MOLST Form Location

- **In the home**
  - Front of refrigerator, by the phone in the kitchen
  - Individual’s bedside table
  - Kept with patient between care settings

- **Health care setting**
  - Front of Medical Chart
  - Hospital and LTC facility
  - Kept with patient between care settings
What to Do at Time of Transfer

• In the home
  – EMS personnel are trained to look for MOLST
  – MOLST should accompany patient at time of transfer

• Health care setting
  – Make copy of the MOLST to keep in the medical chart
  – Original should accompany patient at time of transfer
  – Original should be placed in front of the patient’s chart at new care setting
MOLST 2005 Review and Revision

- MOLST is consistent with New York State law
- New York State Department of Health has approved MOLST
- MOLST can be used in health care settings, including hospitals and nursing homes
- In counties other than Monroe and Onondaga, the NYS Nonhospital DNR form to indicate DNR orders in non-hospital settings should be attached.
- Do Not Intubate Orders cannot be honored in pre-hospital settings
- Chapter Amendment (S.6365 & A.9479)
MOLST Community Pilot

State of New York
Department of Health
Nonhospital Order Not to Resuscitate (DNR Order)

Person's Name: ____________________________

Date of Birth: _____ / _____ / ______

Do not resuscitate the person named above.

Physician's Signature ______________________

Print Name ______________________________

License Number __________________________

Date _____ / _____ / ______

It is the responsibility of the physician to determine, at least every 90 days, whether this order continues to be appropriate, and to indicate this by a note in the person's medical chart.

The issuance of a new form is NOT required, and under the law this order should be considered valid unless it is known that it has been revoked. This order remains valid and must be followed, even if it has not been reviewed within the 90 day period.

D01.374 (292)

Regional Pilot in Monroe and Onondaga Counties, Approved NYSDOH, October 2005

Governor signed MOLST bill, October 11, 2005
EMS personnel will follow orders on the MOLST form for individuals living in Monroe and Onondaga counties:

- **Individuals living in Monroe and Onondaga counties:** A completed MOLST form can replace the NYS Nonhospital DNR form.

- **Individuals living outside Monroe and Onondaga counties:** The NYS Nonhospital DNR form must be completed in addition to the MOLST.
MOLST Community Pilot

- Do Not Intubate (DNI) orders cannot be honored in pre-hospital settings

- Chapter amendment (S.6365 and A.9479) to MOLST Pilot Project legislation
  - Authorizes EMS in Monroe and Onondaga counties to honor Do Not Intubate (DNI) orders prior to full cardiopulmonary arrest when the patient/resident still has pulse and/or is breathing

- MOLST provides “clear and convincing” evidence to EMS Medical Control outside Monroe and Onondaga counties
Monroe & Onondaga Counties Community Implementation Team

- Facilitate the implementation of the pilot
- Ensure adequate training
- Audit appropriate utilization
- Develop and track quality measures
- Establish standardized metrics
- Assist facility implementation throughout state
- Ensure the MOLST program moves beyond the pilot phase
MOLST Community Pilot Updates

- MOLST updates
  - Periodic email updates on status of pilot
  - Contact patricia.bomba@lifethc.com

- Community web
  - www.compassionandsupport.org
Nonhospital DNR Law

- Nonhospital DNR – Must be on “standard form” issued by the Department of Health (by contrast, hospital-based DNR order can be on any form)
- Current “Standard form” – one page form with little detail beyond instruction not to resuscitate
- Nonhospital DNR – Can be honored only if patient is in full cardiopulmonary arrest
- If patient is NOT in full cardiac or respiratory arrest, FULL treatment must be provided
MOLST Pilot Project Legislation (A.8892)

- Permits community pilot of the MOLST program in Monroe and Onondaga Counties
- Allows for use of MOLST form in lieu of NYS Non-Hospital DNR form (DOH 3474)
- Governor Pataki signed legislation on October 11, 2005
- Carve-out: OMH and OMRDD
DNI is not covered in Nonhospital DNR Law (Public Health Law § 2977)

Authorization for EMS to honor Do Not Intubate (DNI) instructions prior to full cardiopulmonary arrest in Monroe and Onondaga Counties during MOLST pilot

Carve-out: OMH and OMRDD

Governor Pataki signed legislation on July 26, 2006
Clear and Convincing Evidence

• “The ideal situation is one in which the patient’s wishes were expressed in some form of a writing, perhaps a “living will,” while he or she was still competent. The existence of the writing suggests the seriousness of purpose and ensures that the court is not being asked to make a life-or-death decision based upon casual remarks.”

In the Matter of Westchester County Medical Center, on behalf of Mary O’Connor, p8
Clear and Convincing Evidence

• “Of course, a requirement of a written expression in every case would be unrealistic. Further, it would unfairly penalize those who lack the skill to place their feelings in writing. For that reason, we must always remain open to applications such as this, which are based upon the repeated oral expressions of the patient.”

In the Matter of Westchester County Medical Center, on behalf of Mary O’Connor, p8
Persons with Mental Retardation

- Patient with MR with capacity can complete MOLST form.
- Health Care Decisions Act for Persons with Mental Retardation (Surrogate’s Court Procedure Act § 1750-b).
- Physician should consult legal counsel for MR patients without capacity. See Surrogate’s Court Procedure Act § 1750-b.
Persons with Developmental Disabilities

- Patient with DD \textit{with capacity} can complete MOLST form

- Legislation Adding Persons with Developmental Disabilities to the Health Care Decisions Act (S.5323)

- Physician should consult legal counsel for DD patients \textit{without capacity}. See Surrogate’s Court Procedure Act § 1750-b.
Community Resources

• MOLST 8-Step Protocol
• MOLST Guidebook
• MOLST Patient & Family Trifold Brochure
• Sample Facility Policies & Procedures
• MOLST Training Manual
• Advance Care Planning Booklet
• Community Conversations on Compassionate Care
• Life Choices Program

For these resources and more, visit
www.compassionandsupport.org
EMS Education and Training

• Educational “Tools”
  – Training curriculum
  – Provider protocols
  – Communication skills: How best to tell the worst news

• Training
  – First responders
  – EMS Personnel
  – Medical Control
Advance Care Planning

Start

Assess Behavioral Readiness to Complete Directive

Provide Information on Advance Directives and Explore DNR Needs

Elicit Patient’s Values and Preferences for End-of-Life Care

Encourage Designation of Health Care Proxy

Consider Introducing the Palliative Care Team

Discuss Palliative Care Options including Hospice

Encourage Patient to discuss wishes with family

Inquire about Desire for Organ Donation and/or Autopsy
Stages of Change Theory
By Prochaska et al.

- Stage I: Precontemplation
- Stage II: Contemplation
- Stage III: Preparation
- Stage IV: Action
- Stage V: Maintenance
Behavioral Readiness to Change

- **Precontemplation**: See no need
- **Contemplation**: Recognize need, but have barriers
- **Preparation**: Ready to complete
- **Action**: Advance Care Directive reflects wishes
- **Maintenance**: Advance Care Directive needs update
• “...along with burning flags and resisting the draft there is another un-American activity...dying...”

• “...our Constitution upholds the rights of life, liberty and the pursuit of happiness...death is not there...”

Elizabeth Cohen
Author, news writer and columnist
EPEC, Binghamton, March 7, 2003
Advance Care Planning Community Goals

• Document the designated agent (surrogate decision maker) in a Health Care Proxy for every patient in primary, acute and long-term care and in palliative and hospice care.

• Document the patient/surrogate preferences for goals of care, treatment options, and setting of care at first assessment and at frequent intervals as condition changes.

National Quality Forum, Framework and Preferred Practices for Quality Palliative Care & Hospice Care, 2006, Adapted for New York State
Advance Care Planning Community Goals

• Convert the patient treatment goals into medical orders and ensure that the information is transferable and applicable across care settings, including long-term care, emergency medical services, and hospital, i.e., the Medical Orders for Life-Sustaining Treatments—MOLST, a POLST Paradigm Program.

*National Quality Forum, Framework and Preferred Practices for Quality Palliative Care & Hospice Care, 2006, Adapted for New York State*
Advance Care Planning Community Goals

- Make advance directives and surrogacy designations available across care settings

- Develop and promote healthcare and community collaborations to promote advance care planning and completion of advance directives for all individuals

*National Quality Forum, Framework and Preferred Practices for Quality Palliative Care & Hospice Care, 2006, Adapted for New York State*
Questions?

www.compassionandsupport.org

“Knowing is not enough; we must apply. Willing is not enough; we must do.”

Goethe