ECHO MOLST for Individuals with Intellectual or Developmental Disabilities (I/DD)
ECHO MOLST for Individuals with Intellectual or Developmental Disabilities (I/DD)

1. MOLST: A Key Pillar of Palliative Care
2. Who Determines Who Has the Right to Make End-of-Life Decisions
3. Safeguarding the Voice of Individuals with IDD
4. Ensuring MOLST is Done Right for Individuals with IDD
5. More Than a Form: MOLST is a process
6. Shared Decision Making and MOLST
7. Addressing Feeding Challenges
Session 1
MOLST: A Key Pillar of Palliative Care

Presenter

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Founder & Emeritus Chair, MOLST Statewide Implementation Team
Co-Founder, National POLST

The speaker has no significant financial conflicts of interest to disclose.
Learning Objectives

• Explain how advance care planning, including MOLST, is a key pillar of palliative care and an integral component of the practice of medicine

• Review a population health approach to advance care planning for the general population and persons with intellectual and developmental disabilities

• Describe differences between standard care, advance directives & medical orders
Advance Care Planning
A Key Pillar of Palliative Care
Palliative Care

Interdisciplinary care

• aims to relieve suffering and improve quality of life for patients with advanced illness and their families

• offered simultaneously with all other appropriate medical treatment from the time of diagnosis

• focuses on quality of life and provides an extra layer of support for patients and families
Palliative Care
Team based care: medical, psychosocial, spiritual, legal

Three Key Pillars
1. Advance Care Planning
   • Advance directives (HCP)
   • Medical orders (MOLST)
2. Pain and symptom management
3. Caregiver education and support

“Best Care” Model for Patients with Serious Illness

Medical Management of Chronic Disease
Integrated with Palliative Care

Goals for Care shift

Death

Bereavement

Progression of Serious Illness

Advance care planning & goals for care, pain and symptom control, caregiver support

Diagnosis

6 mo

12 mo

Hospice

Palliative Care (PC):
Advance Care Planning
A Population Health Approach
Advance Care Planning Conversations

- Occur with a person, their health care agent and primary clinician, and other members of the clinical team
- Are recorded and updated as needed
- Allow for flexible decision making in the context of the patient’s current medical situation.

Advance Care Planning
A Population Health Approach

Advance Directives
(18 and older)
- Health Care Proxy
- Living Will

Medical Orders (MOLST)
(Advanced illness/frailty)
- Resuscitation
- Respiratory Support
- Hospitalization
- Life-Sustaining Treatment

Compassion, Support and Education along the Health-Illness Continuum

- Advancing chronic illness
- Healthy and independent
- Maintain & maximize health and independence
- Resuscitation
- Respiratory Support
- Hospitalization
- Life-Sustaining Treatment

Multiple co-morbidities, with increasing frailty

Death

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Advance Care Planning: Value of Health Care Proxy for Person with I/DD

- Initiate advance care planning process for all people with intellectual or developmental disabilities (I/DD) 18 years of age or older
- If the person with I/DD has the capacity to choose who they trust to make health care decisions, do a Health Care Proxy.
- Discuss and document values, beliefs and what matters most to the individual
- Encourage family members and staff serving those with DD to engage in advance care planning
Community Conversations on Compassionate Care

Storytelling and **Five Easy Steps**

1. Learn about advance directives
   - NYS Health Care Proxy
   - Living Will

2. Identify and Remove barriers

3. Motivate yourself
   - Stories
   - View CCCC videos

4. Complete your HCP
   - Have a conversation
   - Choose the right HCA
   - Discuss what matters
   - Understand LST
   - Put it in writing
   - Share copies

5. Review and Update

Community Conversations on Compassionate Care, a project of the Community-wide End-of-life/Palliative Care Initiative
How to Choose a Health Care Agent

Applies to Choosing a Guardian Who Makes Medical Decisions
Applies to Choosing a Supporter Who Will Help Make Medical Decisions

- Knows me well
- Understands what is important to me
- Will talk about sensitive wishes now
- Will listen to my wishes
- Willing to speak on my behalf
- Would act on my wishes
- Can separate his/her feelings from mine
- Will be available in the future
- Lives close by or willing to come
- Could handle responsibility
- Can manage conflict resolution
- Meets legal criteria
Value of Advance Care Planning:
Complete a Health Care Proxy and Family Discussion

Yes: Patient Wishes Honored. Family at Peace
No: Patient and Family Suffered
Acute Illness, Patient Lacks Decision Making Capacity
Patient Recovers...Not Just at End of Life

Choose the Right HCA. Share What Matters Most

Knowing What Matters Most

Community Conversations on Compassionate Care, a project of the Community-wide End-of-life/Palliative Care Initiative
Advance Care Planning: For Everyone 18 years and Older
Community Conversations on Compassionate Care

WHO WILL SPEAK FOR YOU
if you can't make your own health care decisions?

For everyone ages 18 years and older

Advance Care Planning lets you authorize someone you trust to make your health decisions if or when you can't.

5 easy steps to Advance Care Planning

1. Learn about advance directives (health care proxy and living will).
2. Remove barriers to completing advance directives.
4. Complete your health care proxy and living will. Talk to your family and physician or nurse practitioner about what matters to you.
5. Periodically review and update your advance directives.

Learn more at CompassAndSupport.org.
Ask your physician or nurse practitioner for our free Advance Care Planning booklet.

Conversations change lives. Start your conversation today.

Community Conversations on Compassionate Care, a project of the Community-wide End-of-life/Palliative Care Initiative
Medical Orders for Life-Sustaining Treatment (MOLST)

• Standardized communication process

• **CURRENT** patient health status, prognosis, values & goals for care

• Shared medical decision-making

• Ethical-legal requirements (PHL: HCP & HFCDA and SCPA §1750-b)


• **Physician Accountability**: Patients with I/DD who lack capacity

• Documentation of discussion

• Result: portable medical orders
  • reflect resident preferences for LST they wish to receive and/or avoid
  • common community-wide form
  • **ONLY** form EMS can follow DNR, DNI and Do Not Hospitalize

• Palliative care plan and caregiver support

A project of the Community-wide End-of-life/Palliative Care Initiative
Who is Appropriate for MOLST

• MOLST is generally for patients with advanced illness who require long-term care services and/or who might die within 1-2 years

• The MOLST may also be used for individuals who wish to avoid and/or receive specific life-sustaining treatments
Examples of Advanced Illness

- Severe Heart Disease
- Metastatic Cancer or Malignant Brain Tumor
- Advanced Lung Disease
- Advanced Renal Disease
- Advanced Liver Disease
- Advanced Frailty
- Advanced Neurodegenerative Disease (e.g., Dementia, Parkinson’s Disease, ALS)
Frailty

• Common clinical syndrome in older adults; can occur in individuals with advancing illness of any age

• Carries an increased risk for poor health outcomes including falls, disability, hospitalization, and mortality

• Results from aging-associated decline in reserve and function across multiple physiologic systems such that the ability to cope with every day or acute stressors is compromised

• Clinical features: weak grip, low energy, low physical activity, walks slowly, and may have unintentional weight loss
Individuals at Highest Risk

Advanced chronic conditions coupled with frailty are people at highest risk for:

- recurrent hospitalizations
- worsening frailty
- diminished functional status in everyday life
- mortality

These individuals deserve to be offered the opportunity to learn about and complete a MOLST.
Who is **Not** Appropriate for MOLST

- Healthy people
- People who have a chronic condition or multiple chronic conditions but have a long life expectancy
- Individuals who have an intellectual or developmental disability *only*, *No Advanced Illness and MOLST is governed by SCPA 1750-b*
MOLST Use in Persons with Developmental Disabilities Who Lack Capacity

• All seriously ill persons with developmental disabilities deserve and have a right to receive palliative care

• All seriously ill persons with developmental disabilities are **NOT** appropriate for MOLST

• Consider MOLST when:
  – 1750-b surrogate requests life-sustaining treatment be withdrawn or withheld
  – Person with DD resides in a nursing home
  – Person with DD might die within the next year.

• OPWDD approved use of the MOLST (Memo January 21, 2011)

• Encourage completion of health care proxies

Who is Appropriate for MOLST

1. Patients whose physician, NP or PA would not be surprised if they die in the next 1-2 years
2. Patients who live in a nursing home or receive long-term care services at home or in an adult care facility (e.g. assisted living)
3. Patients who want to avoid and/or receive any or all life-sustaining treatment today
4. Patients who have one or more advanced chronic conditions or a new diagnosis with a poor prognosis
5. Patients who have had two or more unplanned hospital admissions in the last 12 months, coupled with increasing frailty, decreasing functionality, progressive weight loss or lack of social support
MOLST Screening Questions
Persons with Intellectual/Developmental Disabilities (I/DD)

• Does the person with I/DD, their health care agent or the appropriate 1750-b Surrogate express a desire that the person with I/DD avoid or receive any or all life-sustaining treatment?
• Does the person with I/DD live in a nursing home or receive long term care services at home or in a group home?
• Would you be surprised if the person with I/DD dies in the next year?
• Does this person with I/DD have one or more advanced chronic condition (rapidly progressive dementia, end-stage COPD or CHF) or a serious new illness with a poor prognosis (metastatic pancreatic cancer)?
• Does this person with I/DD have decreased function, frailty, progressive weight loss, >= 2 unplanned admissions in last 12 months, have inadequate social supports, or need more help at home?
MOLST Use in Persons with Developmental Disabilities Who Lack Capacity

• A positive response to one or more of the MOLST Screening Questions is a clinical quality trigger that the person with developmental disabilities is appropriate for a thoughtful MOLST discussion.
8-Step MOLST Protocol

1. Prepare for discussion
   - Understand patient’s health status, prognosis & ability to consent
   - Retrieve completed Advance Directives
   - Determine decision-maker & PHL legal requirements

2. Determine what the patient/family know

3. Explore goals, hopes and expectations

4. Suggest realistic goals

5. Respond empathetically

6. Use MOLST to guide choices & finalize patient wishes
   - Shared, informed medical decision-making and conflict resolution

7. Complete and sign MOLST
   - Follow PHL, SCPA §1750-b and document conversation
   - If person lacks capacity & no HCA, physician signs MOLST After OPWDD Checklist is completed and No objection is raised

8. Review and revise periodically

Developed for NYS MOLST, Bomba, 2005; revised 2011

• Developed Based on My Clinical Practice since 1979
• Prior to NY MOLST
MOLST Instructions and Checklists
Ethical Framework/Legal Requirements

**Checklist #1** - Adult patients with medical decision-making capacity *any setting*

**Checklist #2** - Adult patients without medical decision-making capacity who have a health care proxy *any setting*

**Checklist #3** - Adult hospital or nursing home patients without medical decision-making capacity who do not have a health care proxy, and decision-maker is a Public Health Law Surrogate (surrogate selected from the surrogate list); includes hospice

**Checklist #4** - Adult hospital or nursing home patients without medical decision-making capacity who do not have a health care proxy or a Public Health Law Surrogate (+/- hospice eligible)

**Checklist #5** - Adult patients without medical decision-making capacity who do not have a health care proxy, and the MOLST form is being completed in the *community*. [Checklist for Minor Patients - *any setting*]

**Checklist for Developmentally Disabled who lack capacity** — *any setting* must travel with the patient’s MOLST

[http://www.nyhealth.gov/professionals/patients/patient_rights/molst/]
Care Plan

• Palliation
  • Pain and symptom management

• Who Will Assess in an Emergency

• Supportive care
  • Patient
  • Family
  • Staff
Differences between standard care, advance directives & medical orders
Flow of Emergency Care: Standard Medical Care
Flow of Emergency Care: MOLST
<table>
<thead>
<tr>
<th>Characteristics</th>
<th>MOLST</th>
<th>Advance Directives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>For seriously ill with advanced illness, advanced frailty</td>
<td>All adults</td>
</tr>
<tr>
<td>Timeframe</td>
<td><strong>Current care</strong></td>
<td>Future care</td>
</tr>
<tr>
<td>Who completes the form</td>
<td>Physicians, NPs, PAs</td>
<td>Patients</td>
</tr>
<tr>
<td>Resulting form</td>
<td>Medical Orders (MOLST)</td>
<td>Advance Directives</td>
</tr>
<tr>
<td>Health Care Agent or Surrogate role</td>
<td>Can engage in discussion if patient lacks capacity</td>
<td>Cannot complete</td>
</tr>
<tr>
<td>Portability</td>
<td>Physicians, NPs, PAs responsibility Physician <strong>only</strong> for Patients with IDD</td>
<td>Patient/family responsibility</td>
</tr>
<tr>
<td>Periodic review</td>
<td>Physicians, NPs, PAs responsibility Physician <strong>only</strong> for Patients with IDD</td>
<td>Patient/family responsibility</td>
</tr>
</tbody>
</table>

Differences Between MOLST and Advance Directives

Adapted from Bomba PA, Black J. The POLST: An improvement over traditional advance directives. Cleveland Clinic Journal of Medicine. 2012; 79(7): 457-64
Advance Care Planning Population Based Screening Questions

Everyone 18 & Older

- Does the patient have:
  - Health Care Proxy
  - Living Will
  - Oral Advance Directive
  - Guardianship
    - Person and/or property
  - HIPAA
    - Release

What is the patient’s capacity to appoint a health care agent?

Patients with Advanced Illness/Advanced Fraility

- Does patient with advanced illness/frailty have an MOLST/eMOLST?
  - If yes, is MOLST reviewed regularly, considering current health status, prognosis, resident goals for care, COVID-19?
  - If no, why not?

What is the patient’s capacity to make EOL MOLST decisions?
Advance Care Planning is a continuous communication process.

There are differences between standard medical care, advance directives and MOLST.

MOLST is a set of medical orders and not an advance directive.

MOLST is not merely a form to be completed.

MOLST is not for everyone.
Resources
Redesigned CompassionAndSupport.org

A project of the Community-wide End-of-life/Palliative Care Initiative
How MOLST is Done

MOLST is based on communication between the patient and their provider. The 8-step MOLST Protocol outlines the necessary steps.

Subscribe to NY MOLST Update on MOLST.org
Videos

CompassionAndSupportYouTubeChannel (ACP/MOLST video playlists)
http://www.youtube.com/user/CompassionAndSupport?feature=mhee

Demonstrating Thoughtful MOLST Discussions
Hospital & Hospice Settings
Nursing Home Setting

Patient & Family Education
What is a Health Care Proxy? http://goo.gl/H61TQ
How to Choose a Health Care Agent https://youtu.be/DAEHkh0rFpc
Community Partners in Advance Care Planning https://youtu.be/JKEMouEgGh8
References

• Health Care Decisions OPWDD webpage: https://opwdd.ny.gov/providers/health-care-decisions


• Bomba PA, Black J. The POLST: An improvement over traditional advance directives. Cleveland Clinic Journal of Medicine. 2012; 79(7): 457-64

• More at Resources on MOLST.org