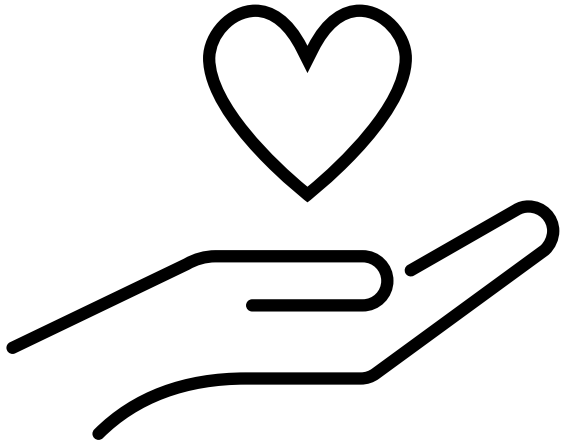


ECHO MOLST for Individuals with Intellectual or Developmental Disabilities (I/DD)

IPRO
Better healthcare, realized.

United Health Services

Project ECHO
Excellus New York

MOLST
MEDICAL ORDERS FOR LIFE-SUSTAINING TREATMENT
A POLST Paradigm Program

HHN HUDSON HEADWATERS HEALTH NETWORK

The Arc New York

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
8. Notifications: Who, What, When and Why

Session 1
MOLST: A Key Pillar of Palliative Care

Presenter

Patricia A. Bomba, MD, MACP, FRCP

Founder, MOLST and eMOLST Programs

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

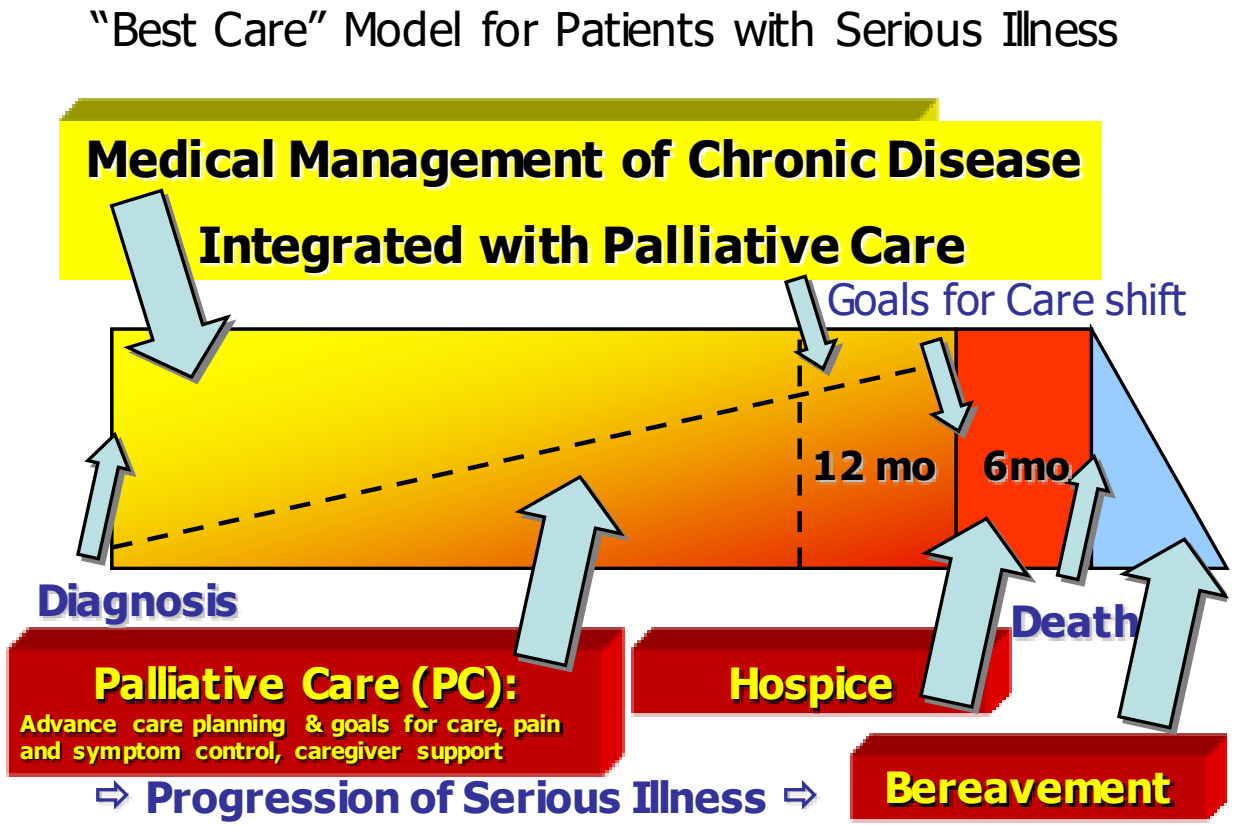
Interdisciplinary care

- 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



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.

IOM Report Dying in America available: http://www.nationalacademies.org/

Advance Care Planning
A Population Health Approach

Advance Directives

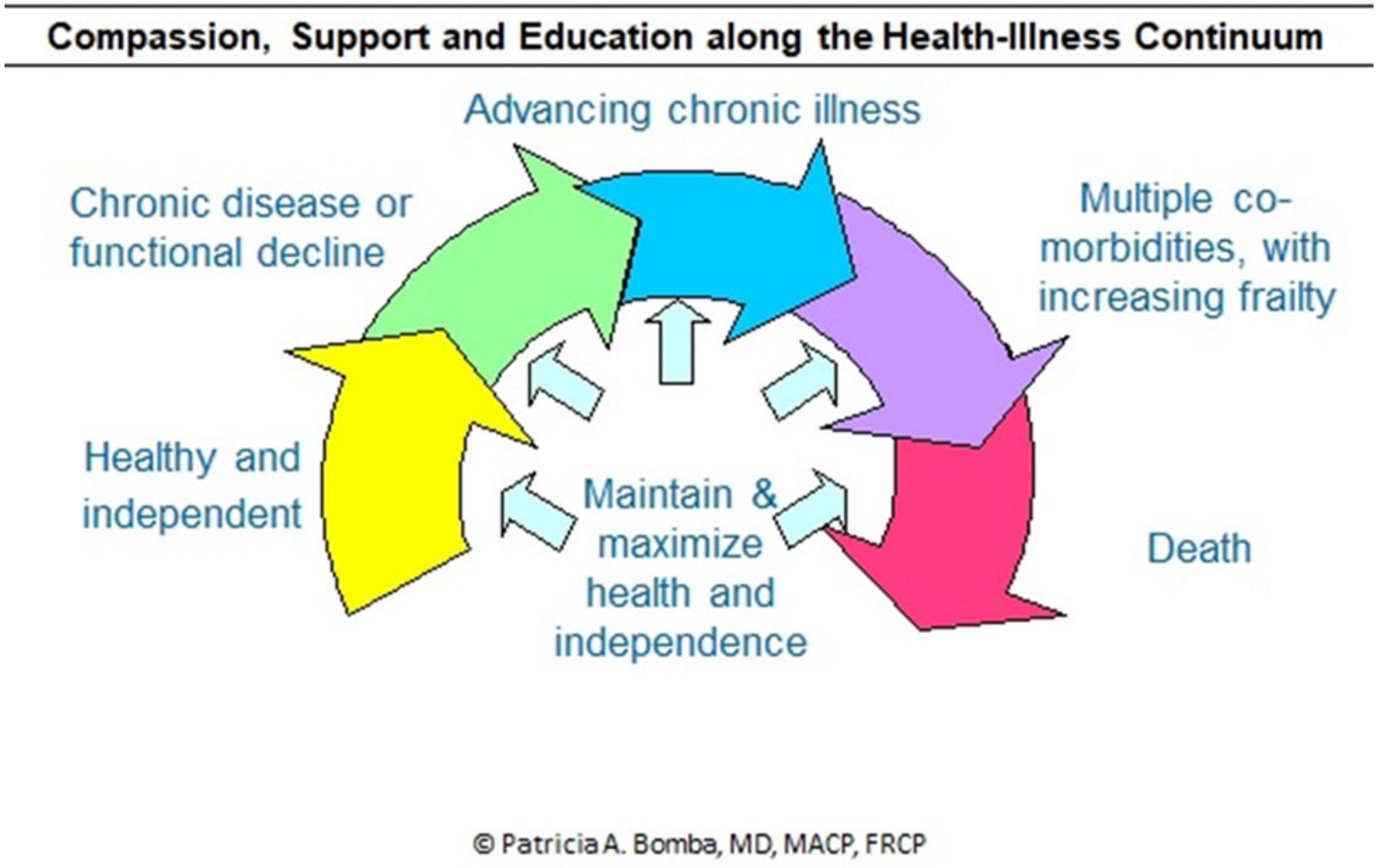
(18 and older)

- Health Care Proxy
- Living Will

Medical Orders (MOLST)

(Advanced illness/frailty)

- Resuscitation
- Respiratory Support
- Hospitalization
- Life-Sustaining Treatment



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

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

Advance Care Planning:
For Everyone 18 years and Older

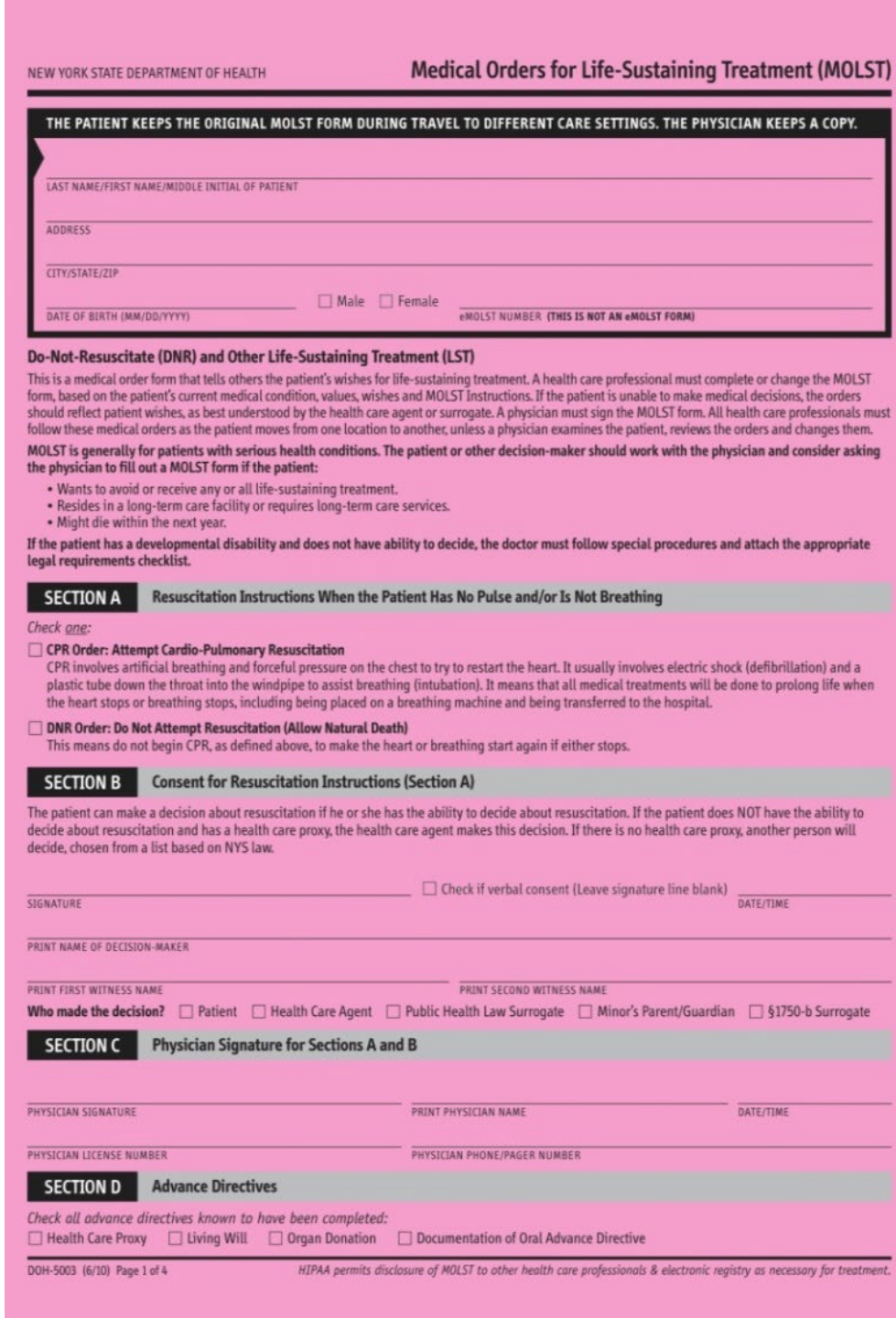
Community Conversations on Compassionate Care

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 & FHCDA and SCPA §1750-b)
- Physician, NP (2018/19), PA (6/17/2020): authority & accountability
- 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



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 KEEPS A COPY.

LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT

ADDRESS

CITY/STATE/ZIP

DATE OF BIRTH (MM/DD/YYYY) ☐ Male ☐ Female eMOLST NUMBER **(THIS IS NOT AN eMOLST 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 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 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 and consider asking the physician 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 a developmental disability and does not have ability to decide, the doctor must follow special procedures and attach the appropriate legal requirements checklist.

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.

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 decision? ☐ Patient ☐ Health Care Agent ☐ Public Health Law Surrogate ☐ Minor's Parent/Guardian ☐ §1750-b Surrogate

SECTION C Physician Signature for Sections A and B

PHYSICIAN SIGNATURE PRINT PHYSICIAN NAME DATE/TIME

PHYSICIAN LICENSE NUMBER PHYSICIAN 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

DOH-5003 (6/10) Page 1 of 4 *HIPAA permits disclosure of MOLST to other health care professionals & electronic registry as necessary for treatment.*

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

http://www.justicecenter.ny.gov/sites/default/files/documents/SDMC-OPWDD-Memo-on-Medical-Orders-for-Life-Sustaining-Treatment.pdf

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

Developed for NYS MOLST, Bomba, 2005; revised 2011

- Developed Based on My Clinical Practice since 1979
- Prior to NY MOLST

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

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

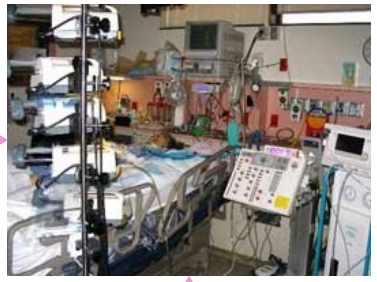
http://www.nyhealth.gov/professionals/patients/patient_rights/molst/

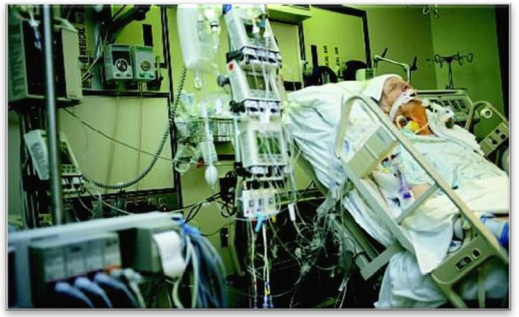
Care Plan

- Palliation
  - Pain and symptom management
- Who Will Assess in an Emergency
- Supportive care
  - Patient
  - Family
  - Staff

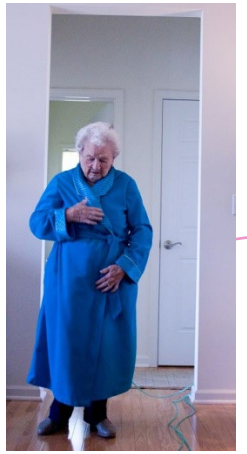
Differences between standard care, advance directives & medical orders

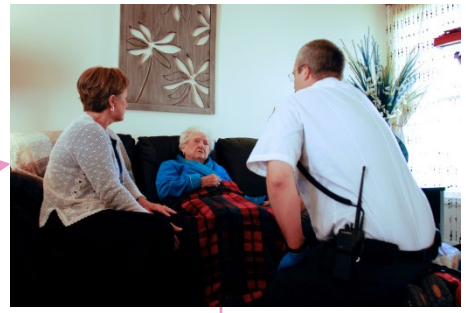
Flow of Emergency Care: Standard Medical Care

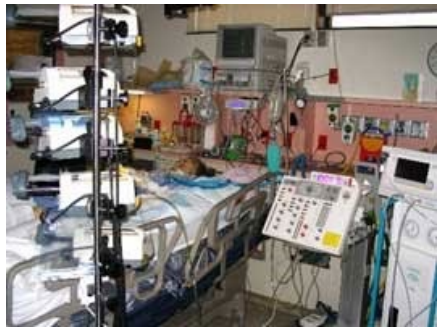


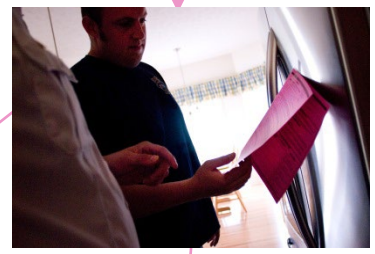


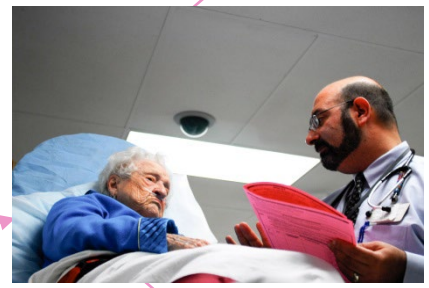
Flow of Emergency Care: MOLST

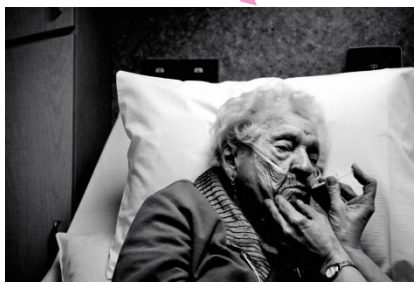












Characteristics	MOLST	Advance Directives
Population	For seriously ill with advanced illness, advanced frailty	All adults
Timeframe	**Current care**	Future care
Who completes the form	Physicians, NPs, PAs	Patients
Resulting form	Medical Orders (MOLST)	Advance Directives
Health Care Agent or Surrogate role	Can engage in discussion if patient lacks capacity	Cannot complete
Portability	Physicians, NPs, PAs responsibility Physician **only** for Patients with IDD	Patient/family responsibility
Periodic review	Physicians, NPs, PAs responsibility Physician **only** for Patients with IDD	Patient/family responsibility

Differences Between MOLST and Advance Directives

MOLST
MEDICAL ORDERS FOR LIFE-SUSTAINING TREATMENT
A POLST Paradigm Program

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 Frailty

Does patient with advanced illness/frailty have an MOLST/eMOLST?

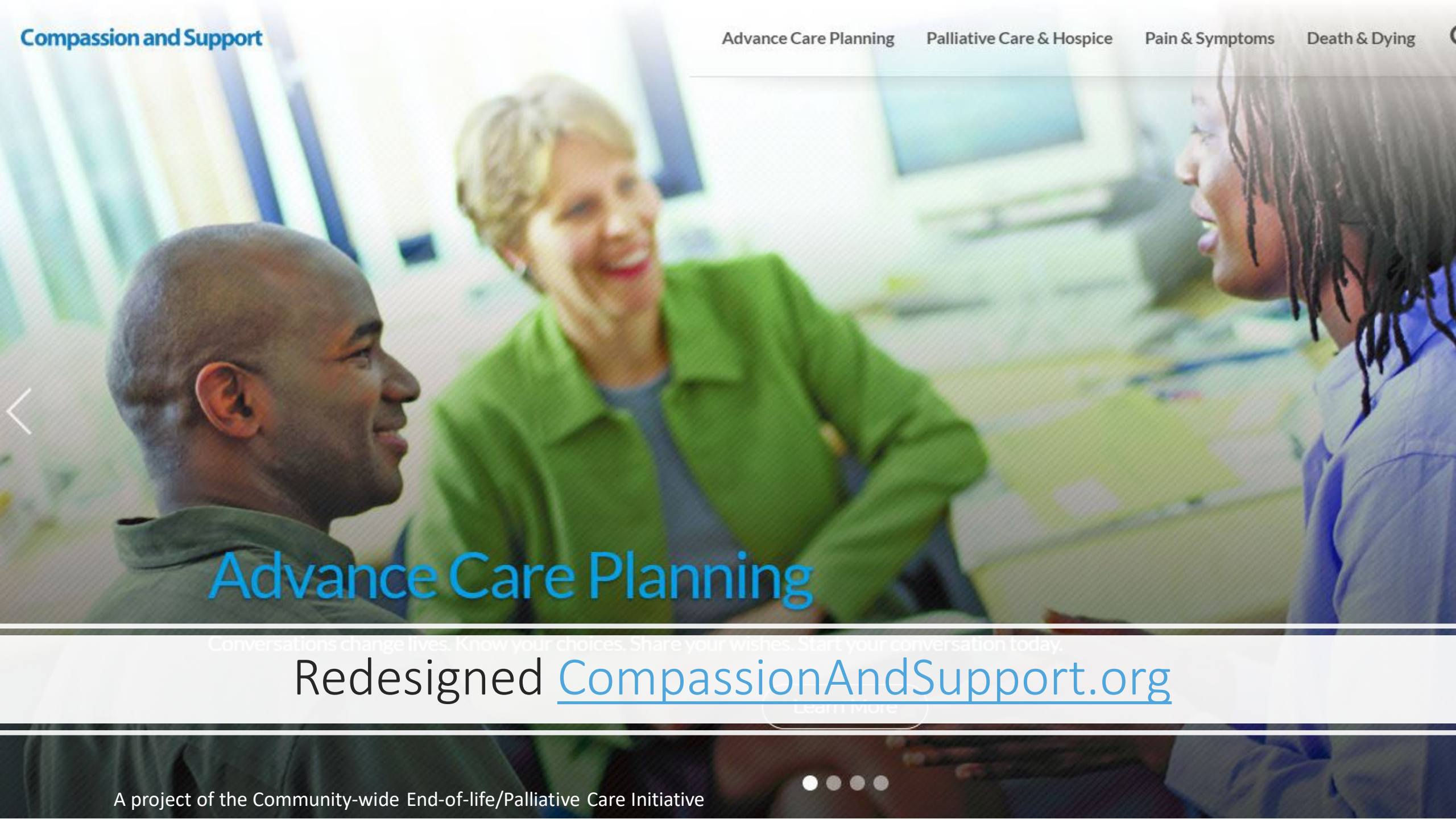
- If yes, is MOLST reviewed regularly, considering current health status, prognosis, resident goals for care, COVID-19?
- If no, why not?

What is the patient's capacity to make EOL MOLST decisions?

Key Points

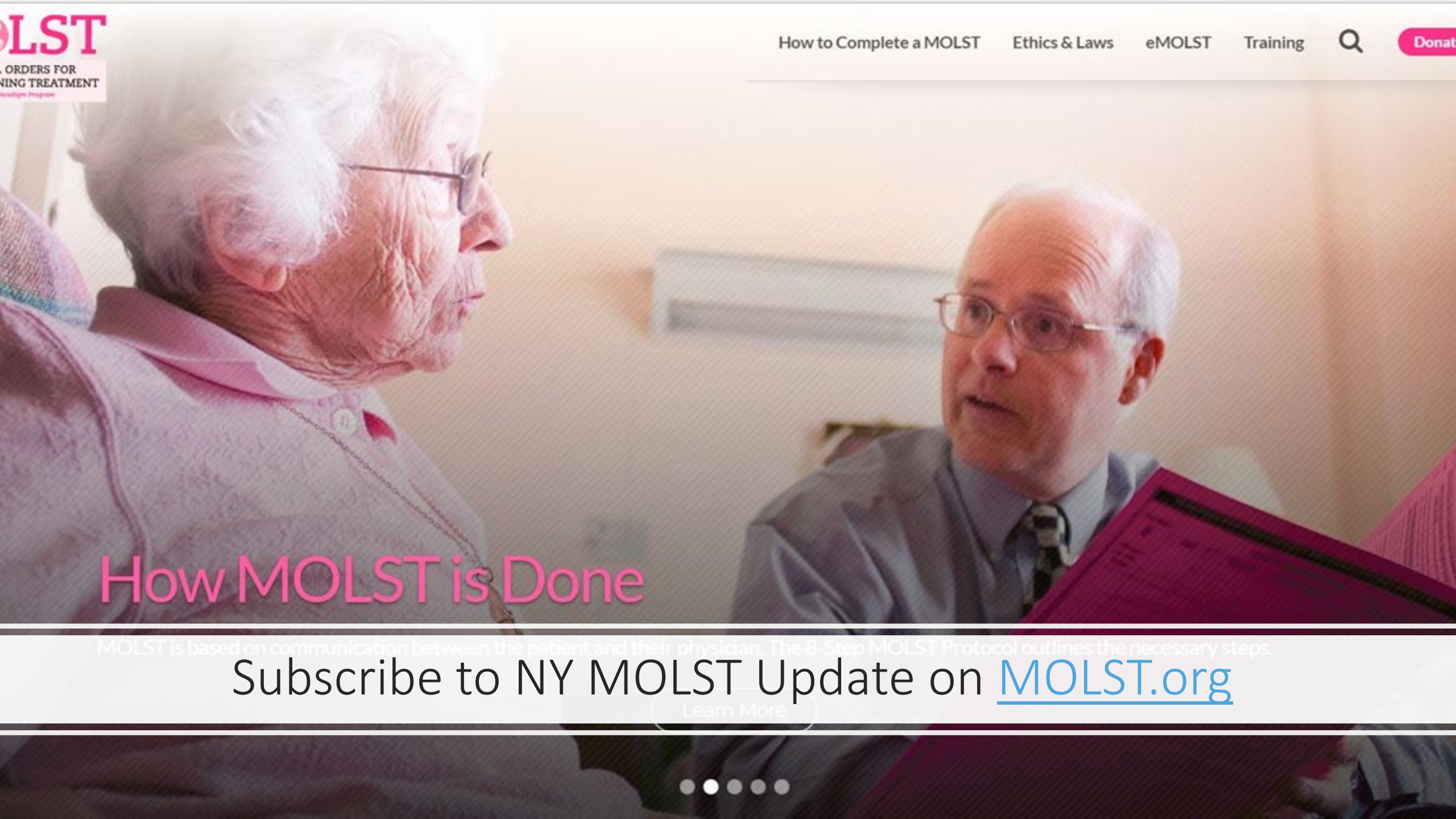
- Advance Care Planning is a continuous communication process.
- There are differences between standard medical care, advance directives and MOLST.
- MOLST is a set of medical orders and not an advance directive.
- MOLST is not merely a form to be completed.
- MOLST is not for everyone.

Resources



Redesigned CompassionAndSupport.org

A project of the Community-wide End-of-life/Palliative Care Initiative



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

Writing Your Final Chapter: Know Your Choices. Share Your Wishes - Original release 2007; revised to comply with FHCDA - MOLST Video Revised 2015! (28:14) https://youtu.be/ClTAG19RX8w

Community Partners in Advance Care Planning

https://youtu.be/JKEMouEgGh8

References

- Health Care Decisions OPWDD webpage: https://opwdd.ny.gov/providers/health-care-decisions
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- Bomba, P. A., & Orem, K. (2015). Lessons learned from New York's community approach to advance care planning and MOLST. Annals of Palliative Medicine, 4(1), 10-21.
- 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