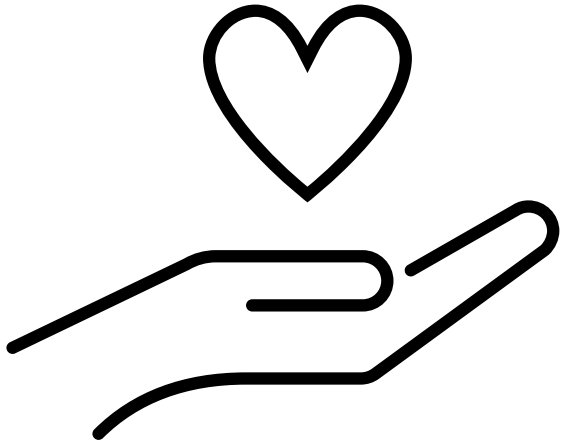

ECHO MOLST for Individuals with Intellectual or Developmental Disabilities (I/DD)

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

Session 6
Shared Decision Making and MOLST

Presenters

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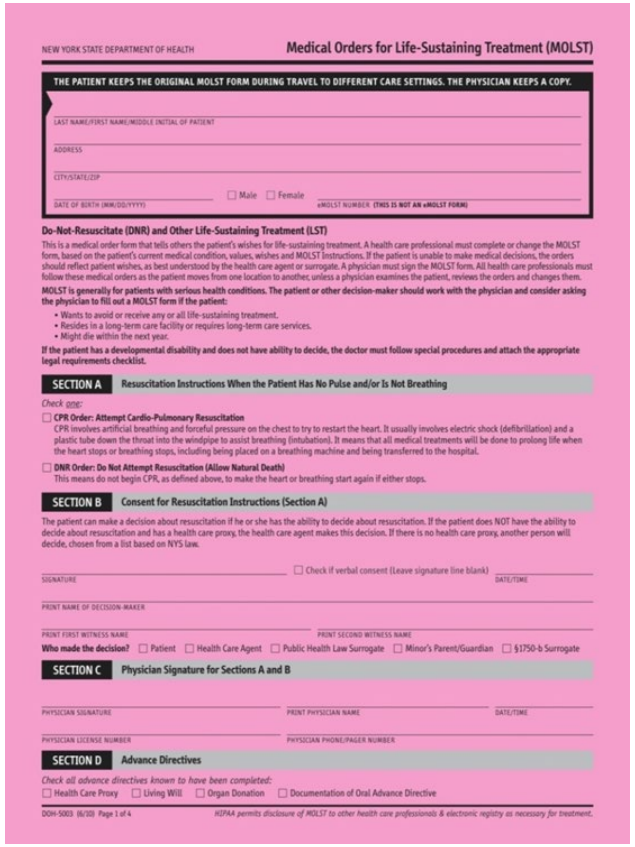
The speakers have no significant financial conflicts of interest to disclose.

Learning Objectives

- Describe and apply the 8-Step MOLST Protocol
- Define shared decision-making process for medical orders
- Identify requirements of guardian/surrogate decision maker
- Explain the determination and proper documentation of necessary medical criteria for decisions to withhold/withdrawal life-sustaining treatments

8-Step MOLST Protocol

Patients Have Right to Make EOL Decisions
Value of MOLST/eMOLST vs. Nonhospital DNR Form vs. Facility Forms



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

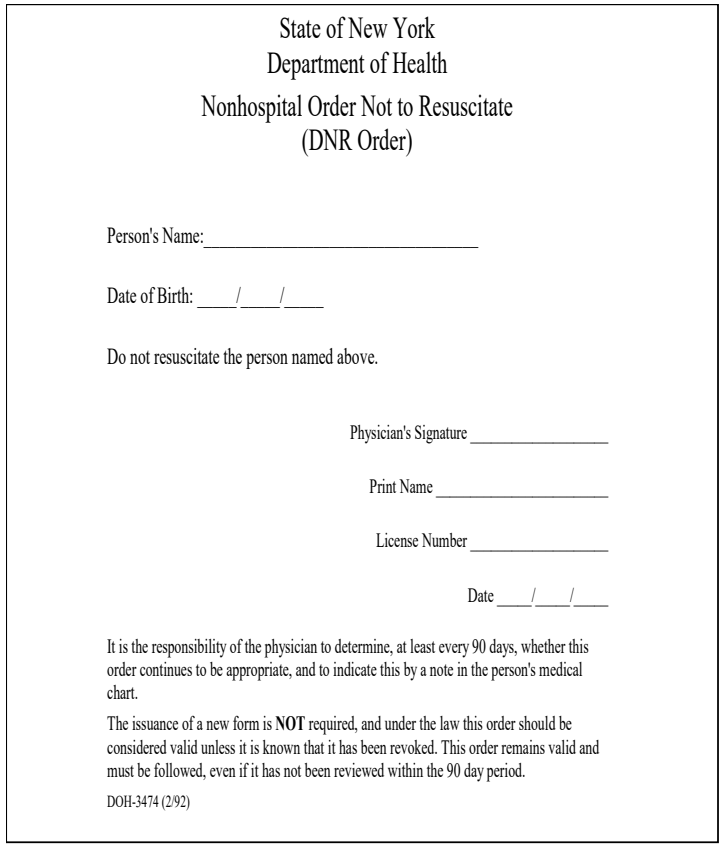
SECTION D Advance Directives

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.*

https://www.health.ny.gov/forms/doh-5003.pdf



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.

DOH-3474 (2/92)

MOLST Requires a Thoughtful Discussion or a Series of Discussions

Communication Challenges

Limited evidence base on end-of-life needs in adult I/DD population, especially those in community residence

Communication barriers

- Impact Symptom Assessment & Management
- Can lead to diagnosis of illness at more advanced stage
- Less involvement of patient in decision making

Patient's lack of comprehension of their illness, symptoms, or treatments

- May interpret illness or treatments as punishment for wrongdoing.
- May not be able to understand death and why their family/caregivers are sad around them.

Ellison & Rosielle. Palliative Care Network of Wisconsin. Fast Facts # 192

Questions to Help a Patient, Health Care Agent or 1750-b Guardian Prepare for a MOLST Discussion

- What do you understand about your current health condition?
- What do you expect for the future?
- What makes life worth living?
- What is important to you?
- What matters most to you?
- How do you define quality of life?
- Would you trade quality of life for more time?
- Would you trade time for quality of life?

MOLST
MEDICAL ORDERS FOR LIFE-SUSTAINING TREATMENT
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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 with IDD 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/

Clinical Frailty Scale

1. **Very Fit –** People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2. **Well –** People who have no active disease symptoms but are less fit than Category 1. Often, they exercise or are very active occasionally, e.g. seasonally.

3. **Managing Well –** People whose medical problems are well controlled, but are not regularly active beyond routine walking.

4. **Vulnerable –** While not dependent on others for daily help, often symptoms limit activities. A common complaint is being "slowed up," and /or being tired during the day.

5. **Mildly Frail –** These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6. **Moderately Frail –** People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need

7. **Severely Frail –** Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8. **Very Severely Frail –** Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9. **Terminally Ill –** Approaching the end of life. This category applies to people with a life expectancy < 6 months, who are not otherwise evidently frail.

Where dementia is present, the degree of frailty usually corresponds to the degree of dementia:

- **Mild dementia –** includes forgetting the details of a recent event, though still remembering the event itself, repeating the same question /story and social withdrawal.
- **Moderate dementia –** recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.
- **Severe dementia –** they cannot do personal care without help.

Assess Health Status:

Clinical Frailty Scale

Estimate and Communicate Prognosis

- Physicians markedly over-estimate prognosis
- Accurate information helps patient/family cope & plan
- Offer a range for average life expectancy
  - days to weeks
  - weeks to 3 months
  - 3 – 6 months (PCIA, PCAA, Hospice*)
  - 6 months to 1-2 years (MOLST**)
  - > 1year (MOLST: e.g. persons of advanced age may have explicit wishes.)

* Would it surprise you if this person died in the next 6 months?

** Would it surprise you if this person died in the next 1-2years?

Care Plan

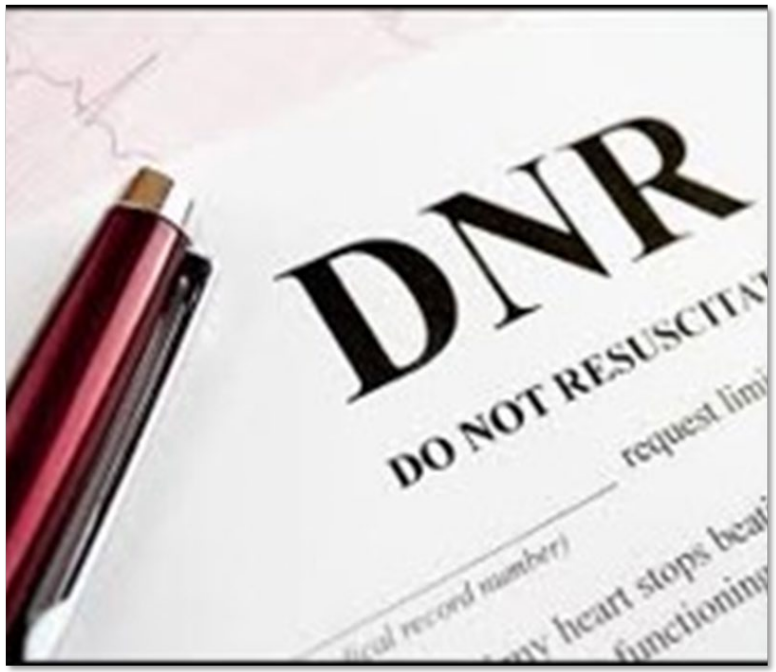
- Palliation
  - Pain and symptom management
- Who Will Assess in an Emergency
- Supportive care
  - Patient
  - Family
  - Staff

Shared Decision-Making

Shared, Informed Medical Decision Making

Will treatment make a difference?	
What are the burdens and benefits?	• Will treatment help or harm the patient?
Is there hope of recovery?	• If so, what will life be like afterward?
What does the patient value?	• What are the patient's goals for care?

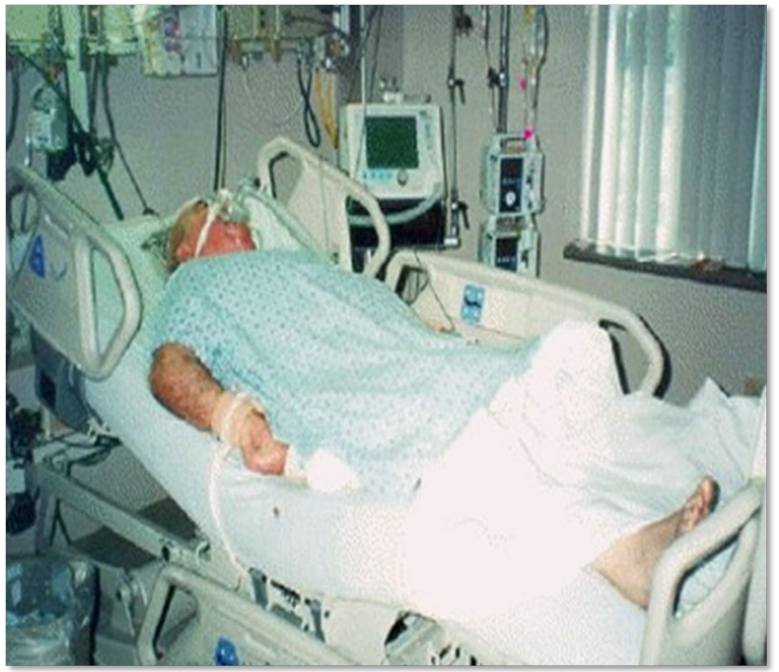
Resuscitation Preferences
Cardiac Arrest



- Define CPR
- Success rate of CPR
  - Advanced illness ≤ 2.0%
  - Moderate frailty-terminal illness: <2%
- Reality of COVID-19
- DNR: Do Not Attempt Resuscitation (Allow Natural Death)
- DNR and DNI are distinct medical orders
- DNR does **NOT** mean Do Not Treat

Respiratory Support
Cardiac or Pulmonary Insufficiency

- Survival rates depend on:
  - Factors present at start of ventilator support
  - Development of complications
  - Patient management in ICU
  - Patients with advanced illness/frailty: high risk
- 2012 Study 1019 patients: Six-month mortality rates*
  - 51% in very old patients
  - 67% for DNI patients
  - 77% in case of NIV failure and endotracheal intubation
- Trial period
  - determine if there is benefit based on the patient's current goals for care



*Schortgen, F., Follin, A., Piccari, L., Roche-Campo, F., Carteaux, G., Taillandier-Heriche, E., . . . Brochard, L. (2012). Results of Noninvasive Ventilation in Very Old Patients. Annals of Intensive Care, 2(5). doi:10.1186/2110-5820-2-5

Defining a Trial Period

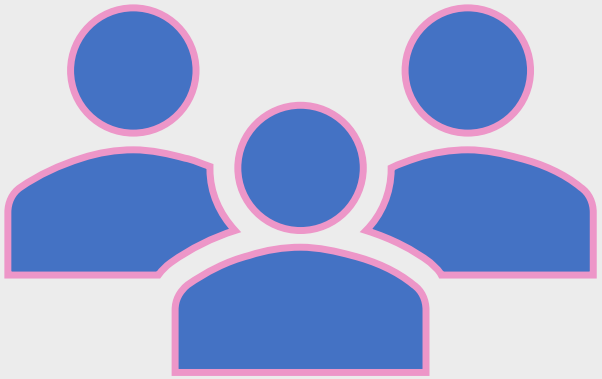
- A trial of life-sustaining treatment may be ordered if the physician or NP or PA agrees it is medically appropriate.
- A trial is used to determine if there is benefit to the patient. A trial is based on the patient's current goals for care.
- If a life-sustaining treatment is started but turns out not to be helpful and does not meet the patient's goals for care, treatment can be stopped.
- Additional procedures may be needed for patients with developmental disabilities (see page 4).

Hospitalization/Transfer Preferences

- A patient who does not wish to go back to the hospital needs
  - Palliative care plan
  - 24/7 plan for assessment if an emergency arises
  - 24/7 plan for management of pain and symptoms
  - Provision of basic care needs in the current setting
  - Caregiver education, support and respite
- Assessment is required if an acute issue arises, and the patient does not wish to be hospitalized

Conflict Resolution

- Manage conflict within the family, within the team and between the patient/family and team with skill and empathy
- Apply the approach to a crucial conversation to resolve conflict



Requirements for a §SCPA 1750-b Surrogate

Ethical Hierarchy of Medical Decision-Making

Patient's Current Wishes

- If the patient has decisional capacity, this **ALWAYS** takes precedence.

Substituted judgment

- Done by the Health Care Agent or §SCPA 1750-b surrogate - only when the patient is not fully capable of making decisions
- Based on the patient's prior values & wishes
- Making decisions as the patient would
- Advance directive is used as a *guide*
- Patient input, when possible, even if patient is not fully capable of making the decision

Ethical Hierarchy of Medical Decision-Making

- Best interest
  - Done by the Health Care Agent or §SCPA 1750-b surrogate when the patient lacks decisional capacity and evidence does not exist for substituted judgment
  - Balancing benefits and burdens
  - Input from caregivers is important, but must focus on the patient's – not the caregiver's best interest
  - Using values and beliefs, when there is no surrogate, and no knowledge of patient values, beliefs, goals or prior wishes with respect to end-of-life care

Responsibility of Surrogates

Advocate for efficacious treatment.

Base decisions on best interests, and when known, the person's wishes including moral and religious beliefs.

Statutory best interest considerations include - dignity and uniqueness of the person, preserve, improve or restore health; relief from suffering.

SCPA 1750-b (2) & (4)

Necessary Medical Criteria to WH/WD LST

Life Sustaining Treatment (LST)

Medical treatment which is sustaining life functions and without which, according to reasonable medical judgment, the patient will die within a relatively short time period.

Includes CPR, mechanical ventilation, hemodialysis, and artificial nutrition and hydration.

SCPA 1750-b(1)

Role of Physician - Medical Criteria

Attending/concurring physician determine to a reasonable degree of certainty

1. patient has a terminal condition; OR
2. is permanently unconscious; OR
3. *has a medical condition other (other than a developmental disability) that is irreversible and will continue indefinitely; (COPD, CHF, dementia)*
4. **AND**, the proposed treatment would impose an extraordinary burden to the individual.

SCPA 1750-b(4)(b)

Extraordinary Burden Considerations

1. the person's medical condition other than the person's developmental disability
2. the expected outcome of the LST, notwithstanding the person's developmental disability

SCPA 1750-b(4)(b)

Role of Physician - Artificial Hydration and Nutrition

Additional requirement of finding that ANH itself poses an extraordinary burden to the person

OR

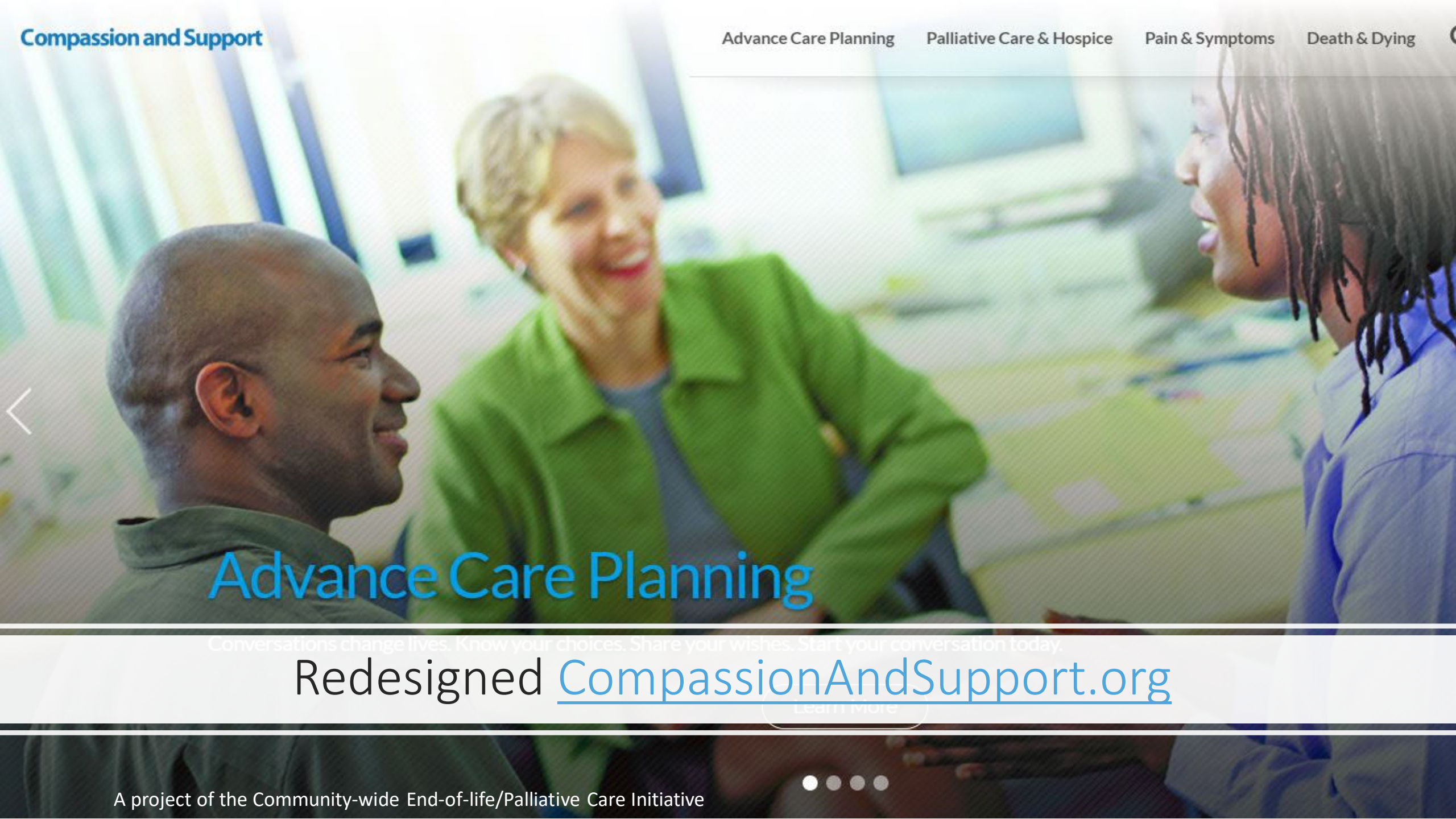
There is no reasonable hope of maintaining life

SCPA 1750-b(4)(b)

Key Points

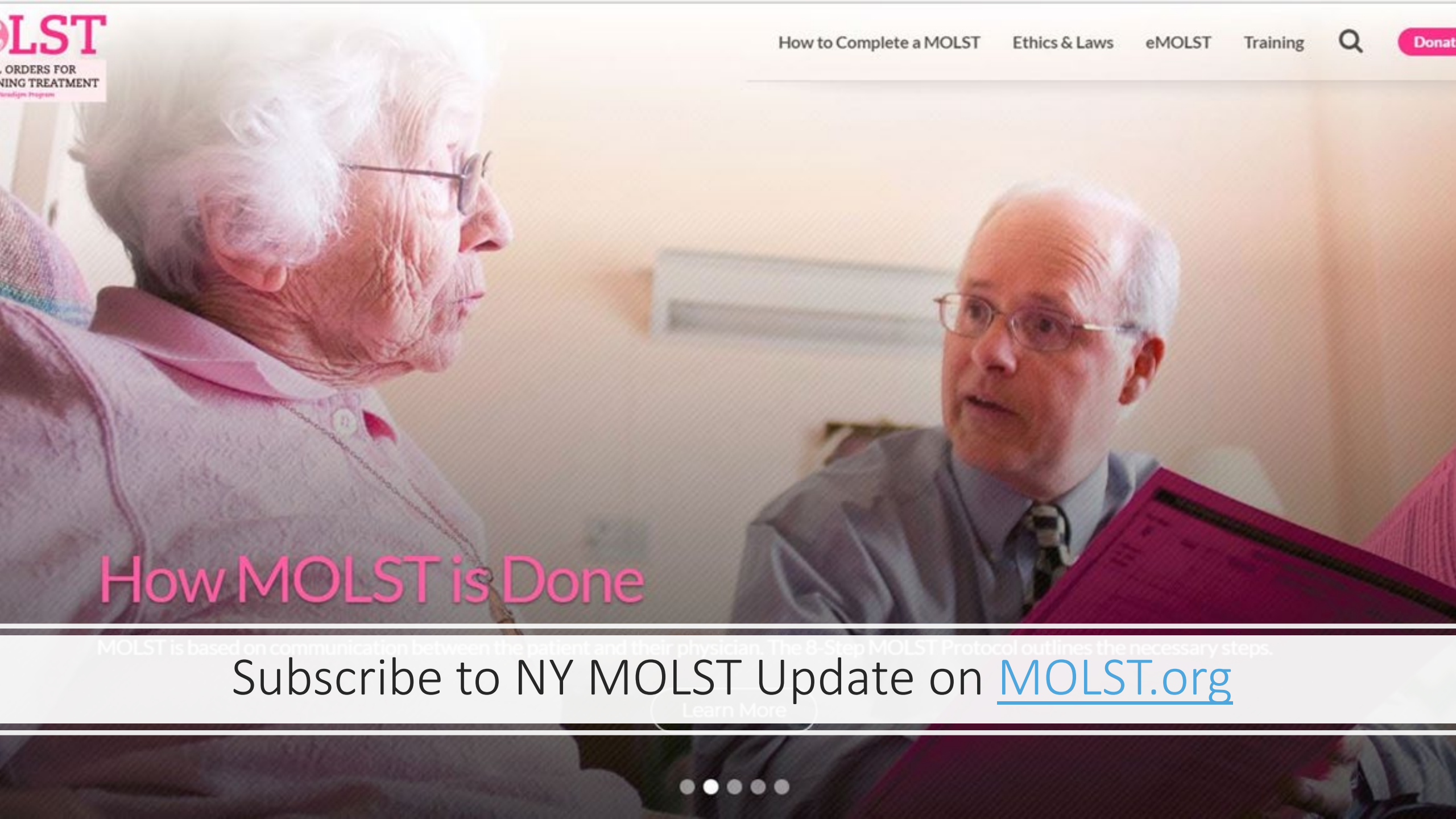
- MOLST requires thoughtful discussion that ensures well informed shared decision-making.
- The 8-Step MOLST Protocol is integrated with the OPWDD Checklist to ensure proper completion of MOLST.
- The attending and concurring physician are responsible for determining medical criteria.
- The attending and concurring physician are responsible for determining extraordinary burden.
- MOLST is not merely a form to be completed.
- Additional requirements exist for feeding tubes and will be addressed in a separate session.

Resources



Redesigned CompassionAndSupport.org

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



Subscribe to NY MOLST Update on MOLST.org

Web Resources

- Thoughtful MOLST Discussions: 8-Step MOLST Protocol
- MOLST Form and individual web pages
  - Resuscitation Preferences
  - Respiratory Support
  - Future Hospitalization/Transfer
  - Feeding Tubes
  - Antibiotics
  - Dialysis
  - Other Instructions
  - Review and Renew

Videos

Demonstrating Thoughtful MOLST Discussions

- Hospital & Hospice Settings
- Nursing Home Setting

Patient & Family Education

- 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

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

New CPT Codes for ACP & MOLST Discussions (02/02/16 Webinar Recording)
https://youtu.be/VCV26ZyGgwY

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- More at Resources on MOLST.org

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- Abbey Pain Scale https://www.apsoc.org.au/PDF/Publications/APS_Pain-in-RACF-2_Abbey_Pain_Scale.pdf
- Books Beyond Words https://booksbeyondwords.co.uk/
- Disability Distress and Assessment Tool (DisDAT) https://www.wamhinpc.org.uk/sites/default/files/Dis%20DAT_Tool.pdf
- Vital Talk - evidence based communication techniques for clinicians www.vitaltalk.org/