



ALBANY MED Health System

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# **Palliative Care in Patients with Developmental Disabilities**

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# Disclosures

- I have no relevant financial relationship(s) with ineligible companies to disclose.

# Learning Objectives

- To understand the difference between palliative care and hospice care
- To be able to identify patients that may benefit from palliative care consultation.

# Palliative Medicine

- What is palliative medicine
- History of palliative medicine
- What is hospice care
- MOLSTS
- Cases



# Palliative Medicine

- Provide patients and their families with relief of symptoms, pain and stress of a serious illness
- Improve quality of life for both the patient and family during a serious illness
- Improve communication/family understanding
- Suffering is experienced by persons, not just bodies (Cassel et al)



# History of Palliative Care

- Cicely Saunders – social worker, nurse and physician in the UK
  - Total pain
  - Hospice 1967
  - Reached adult care in America in 1970s
  - Pediatrics in late 1970s
- Medical specialty in 1987
- Pediatrics really starting to grow in the early 2000s



# Medical Complexity

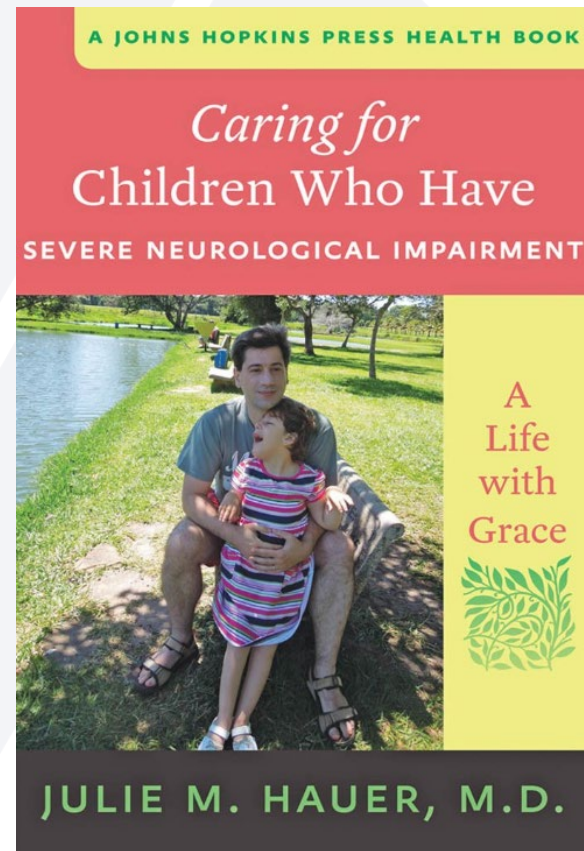
- Children with medical complexity (CMC)
- Most medically fragile subgroup of children with special healthcare needs. Increasing in prevalence.
  - Intensive hospital and /or community-based service needs
  - Reliance on technology, polypharmacy and/or home care or congregate care to maintain basic quality of life
  - Risk of frequent and prolonged hospitalizations which leads to high health-resource utilization and
  - An elevated need for care coordination

Cohan et al.



# Severe neurological impairment (SNI)

- Subgroup of patients with developmental disability
- Patients with SNI have developmental disability and are medically complex
- Dr. Julie Hauer: *Caring for Children with Severe Neurological Impairment, A Life with Grace*





# Types of Patients

- Life threatening illness
- Life shortening illness
  - \*Values\*
- Patients at the end of their life
- Medical complexity verse palliative care



# How We Can Help

- Symptom management, psychosocial support, spiritual support, communication support, decision-making support, prognostication
- Moral distress verse ethical concern
- Discussing compassionate discontinuation of medical technology, or helping determine what is ineffective medical care for a specific patient



# Prognosis

- Not just about quantity
- Discussing prognosis does not take away hope (Mack et al)
- Most patients and parents want detailed information about prognosis (Ilowite et al)



# Value based decisions

- What is important to the patient, what brings them joy
- What do they perceive as suffering
- Quality of life



# Hospice

- Prognosis
- Physician, nurse, chaplain, social work, child life
- Vast majority outpatient, inpatient facilities
- Still a spectrum of medical life-prolonging therapies
- Do NOT have to be DNR
- Concurrent care for pediatrics, prognosis plus goals
  - Medicaid, some private insurance, state dependent



# MOLSTS

- Medical Order Life Sustaining Technology
- For patients with ID/DD need the DD checklist
- Licensed psychologist or specially appointment physician to agree patient does not have capacity for these decisions and there is no HCA
- Based on medical condition that does NOT include consideration of their intellectual or developmental disability



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

This Medical Orders for Life-Sustaining Treatment (MOLST) form 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. A physician, nurse practitioner, or physician assistant reviews the patient's current health status, prognosis, goals for care, and the risks and benefits of each life-sustaining treatment with the patient if they have capacity, or the health care agent or surrogate if the patient lacks capacity.

All ethical and legal requirements must be followed, including special procedures when a patient has an intellectual or developmental disability and lacks capacity. If the patient has an intellectual or developmental disability (I/DD) and lacks the capacity to decide, the physician (not a nurse practitioner or physician's assistant) must follow special procedures and attach the completed Office for People with Developmental Disabilities (OPWDD) MOLST Legal Requirements Checklist for Individuals with I/DD before signing the MOLST. (OPWDD checklist available at <https://opwdd.ny.gov/providers/health-care-decisions>). For more information on requirements for completing the MOLST, see page 4.

This MOLST may not be changed without the consent of the patient (or their health care decision-maker if the patient lacks capacity). Completing a MOLST is voluntary and cannot be required. The patient should keep this original MOLST with them at all times, whenever they leave home and during travel to different care settings. The physician, nurse practitioner, or physician assistant keeps a copy. All health care professionals and emergency medical services (EMS) providers are required to follow these medical orders. HIPAA permits disclosure of MOLST to other health care professionals & electronic registry as necessary for treatment. For further information on MOLST, see [https://www.health.ny.gov/professionals/patients/patient\\_rights/molst/](https://www.health.ny.gov/professionals/patients/patient_rights/molst/)

### SECTION A Patient Information

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

ADDRESS, CITY, STATE, ZIP \_\_\_\_\_

PREFERRED PHONE NUMBER \_\_\_\_\_

DATE OF BIRTH (MM/DD/YYYY) \_\_\_\_\_

\*MOLST NUMBER (THIS IS NOT AN \*MOLST FORM) \_\_\_\_\_

**Check All Advance Directives Known to be Completed**

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

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

Check **one**:

CPR Order: Attempt Cardio-Pulmonary Resuscitation  
 DNR Order: Do Not Attempt Resuscitation (Allow Natural Death)

### SECTION C Orders for Life-Sustaining Treatment When the Patient Has a Pulse and is Breathing

**Respiratory Support: Non-invasive Ventilation and/or Intubation and Mechanical Ventilation**

Check **one**:  Intubation and long-term mechanical ventilation, includes tracheostomy  
 A trial of non-invasive ventilation and/or intubation and mechanical ventilation\*  
 A trial of non-invasive ventilation only, if fails, Do Not Intubate\*  
 Do Not Intubate (DNI) and Do Not Use Non-invasive Ventilation or Mechanical Ventilation

**Future Hospitalization/Transfer**

Check **one**:  Send to the hospital, when medically necessary  
 Send to the hospital only if pain and severe symptoms cannot be controlled  
 Do not send to the hospital

### SECTION D Consent for Sections B and C

SIGNATURE OF INDIVIDUAL MAKING DECISIONS \_\_\_\_\_

PRINTED NAME OF INDIVIDUAL MAKING DECISIONS \_\_\_\_\_

Verbal consent, leave signature line blank

DATE/TIME OF CONSENT \_\_\_\_\_

**Who is the individual making decisions:**

Patient  Health Care Agent  FHCDA Surrogate  Minor's Parent/Guardian  §1750-b Surrogate for individual with I/DD

PRINTED NAME OF FIRST WITNESS\* \_\_\_\_\_

PRINTED NAME OF SECOND WITNESS \_\_\_\_\_

\*If this decision relates to an individual with an intellectual or developmental disability, refer to the instructions on page 4 before proceeding.

### SECTION E Physician/Nurse Practitioner/Physician Assistant Signature for Sections B and C

If Section D is completed by a §1750-b Surrogate, a physician must sign this Section E. Prior to the physician signing this Section E when Section D is completed by a §1750-b Surrogate, the physician must complete and attach the OPWDD Checklist.

SIGNATURE \_\_\_\_\_

PRINT NAME \_\_\_\_\_

LICENSE NUMBER \_\_\_\_\_

DATE/TIME \_\_\_\_\_

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

DATE OF BIRTH (MM/DD/YYYY) \_\_\_\_\_

### SECTION F Additional Orders for Life-Sustaining Treatment

**TREATMENT GUIDELINES**

Check **one**:

No limitation on medical interventions  
 Limited medical interventions, only as described below  
 Comfort measures only. Provide medical care and treatment with the primary goal of relieving pain and other symptoms

**ARTIFICIALLY ADMINISTERED FLUID AND NUTRITION**

**FEEDING TUBE**

Check **one**:  Long term feeding tube  
 Determine use or limitation if need arises\*  
 No feeding tube

**IV FLUIDS**

Check **one**:  IV fluids  
 Determine use or limitation as need arises\*  
 No IV fluids

**ANTIBIOTICS**

Check **one**:  Use antibiotics to treat infections  
 Determine use or limitation of antibiotics when infection occurs\*  
 Do not use antibiotics

**DIALYSIS**

Check **one**:  Use dialysis to treat renal failure  
 Determine use or limitation if renal failure occurs\*  
 Do not use dialysis

**OTHER MEDICAL ORDERS AND INSTRUCTIONS** (only as discussed with the physician, NP, or PA. May include instructions and goals for trials\*. If nothing else is discussed, write NONE.)  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

### SECTION G Consent for Section F

SIGNATURE OF INDIVIDUAL MAKING DECISIONS \_\_\_\_\_

PRINTED NAME OF INDIVIDUAL MAKING DECISIONS \_\_\_\_\_

Verbal consent, leave signature line blank

DATE/TIME OF CONSENT \_\_\_\_\_

**Who is the individual making decisions:**

Patient  Health Care Agent  FHCDA Surrogate  Minor's Parent/Guardian  §1750-b Surrogate for individual with I/DD

PRINTED NAME OF FIRST WITNESS\* \_\_\_\_\_

PRINTED NAME OF SECOND WITNESS \_\_\_\_\_

\*If this decision relates to an individual with an intellectual or developmental disability, refer to the instructions on page 4 before proceeding.

### SECTION H Physician/Nurse Practitioner/Physician Assistant Signature for Section F

If consent for this order was provided by a §1750-b Surrogate for an individual with an intellectual or developmental disability, only a physician may sign this section, and only after the OPWDD MOLST Legal Requirements Checklist for Individuals with I/DD has been completed and attached. L

SIGNATURE \_\_\_\_\_

PRINT NAME \_\_\_\_\_

LICENSE NUMBER \_\_\_\_\_

DATE/TIME \_\_\_\_\_

LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT	DATE OF BIRTH (MM/DD/YYYY)
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**SECTION I Review and Renewal**

A physician, nurse practitioner, or physician assistant should review this form at least every 90 days and whenever the patient or other decisionmaker changes their mind about treatment. The MOLST should also be reviewed if the patient moves from one location to another to receive care, or if the patient has a major change in health status (for better or worse).

This MOLST remains valid and must be followed even if it has not been reviewed in the 90-day period.

Date/Time	Reviewer's Printed Name and Signature	Location of Review	Outcome of Review
			<input type="checkbox"/> No change <input type="checkbox"/> Form changed, new form completed <input type="checkbox"/> Form voided, no new form
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LAST NAME/FIRST NAME/MIDDLE INITIAL OF PATIENT	DATE OF BIRTH (MM/DD/YYYY)
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In addition to the MOLST form, the New York State Department of Health and OPWDD have developed legal requirements checklists and instructions to assist in the proper completion of the MOLST. The checklists are intended to assist providers in satisfying the ethical and legal requirements associated with decisions concerning life-sustaining treatment for all patients.

**Adult Patients**

The instructions and legal requirements checklists for **adult patients** can be found at [www.health.ny.gov/professionals/patients/patient\\_rights/molst/](http://www.health.ny.gov/professionals/patients/patient_rights/molst/). For adult patients, there are five different checklists. The correct checklist should be chosen based on the patient's decision-making capacity and the setting.

- **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, hospice or nursing home patients without medical decision-making capacity who do not have a health care proxy, decision-maker is Public Health Law Surrogate
- **Checklist # 4** Adult hospital, hospice or nursing home patients without medical decision-making capacity who do not have a health care proxy and for whom no surrogate from the list is available
- **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

A Public Health Law Surrogate (aka a FHCDA Surrogate) means a surrogate under Public Health Law Article 29-CC (the Family Health Care Decisions Act).

**Minor Patients**

The instructions and legal requirements checklists for **minor patients** can be found at: [www.health.ny.gov/professionals/patients/patient\\_rights/molst/](http://www.health.ny.gov/professionals/patients/patient_rights/molst/)

**Individuals with Intellectual or Developmental Disabilities (I/DD)**

The law governing the decision-making process differs for individuals with I/DD. Surrogate's Court Procedure Act Section 1750-b (SCPA 1750-b) must be followed when making a decision for an individual with I/DD who is determined to lack capacity and who does not have a health care proxy.

- **Sections E and H of this form may only be signed by a physician**, not a nurse practitioner or physician's assistant.
- In sections D and G of this form, **one witness must be the individual's treating physician**.
- Completion of the OPWDD MOLST Legal Requirements Checklist for Individuals with I/DD, including notification of certain parties and resolution of any objections, is **mandatory prior to completion of a MOLST**.
- Both the OPWDD MOLST Legal Requirements Checklist for Individuals with I/DD and SCPA 1750-b process apply to individuals with I/DD, **regardless of their age or residential setting**.
- **Decisions to withhold or withdraw life sustaining treatment (LST) for an individual with I/DD** must be specifically listed and described in step 2 of the OPWDD MOLST Legal Requirements Checklist for Individuals with I/DD and only after the surrogate has had a discussion with the individual's treating physician regarding their medical condition, possible treatment options and goals for care. SCPA 1750-b also requires that two physicians determine that the individual's condition meets specific medical criteria **at the time the request to withhold or withdraw treatment is being made**, including that the provision of the life sustaining treatment would impose an extraordinary burden on the individual. These requirements are included in step 4 of the OPWDD MOLST Legal Requirements Checklist for Individuals with I/DD. The individual's medical condition for the purposes of a request to withhold or withdraw LST **must never include consideration of their intellectual or developmental disability**.
- Trials for an individual with I/DD: Whether or not a new checklist is required following an unsuccessful trial of LST depends on the parameters of the trial, as specified in step 2 of the OPWDD MOLST Legal Requirements Checklist for individuals with I/DD. **If a trial period is open ended, and the authorized surrogate subsequently decides to request withdrawal of the LST, a new checklist is required.**

The complete instructions and legal requirements checklists for **people with intellectual or developmental disabilities** can be found at: [www.opwdd.ny.gov/providers/health-care-decisions](http://www.opwdd.ny.gov/providers/health-care-decisions) or at [www.health.ny.gov/professionals/patients/patient\\_rights/molst/](http://www.health.ny.gov/professionals/patients/patient_rights/molst/).



# Case study 1

- 17 year old male with severe developmental disability
- Worsening intestinal motility
- Requires GJ tube



## Case study 2

- 33 year old female with moderate developmental disability and congenital heart disease with worsening heart failure due valve regurgitation



## Case study 3

- 25 year old female with moderate to severe developmental disability.
- Had tracheostomy but has since removed
- Repeated admissions for worsening respiratory status
- ICU says she has “no quality of life” ....



# References

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