The Arc New York

A family-based organization for people with intellectual and developmental disabilities

Achieve with us.

End of Life Decisions and Aging in Place: The Challenges of Supporting Individuals with Increased Complex Medical Needs

End of Life Decisions and Aging in Place

John H.T. Dow, Esq., Assistant General Counsel, The Arc New York – Moderator

Shannon Stockwell, Esq., Deputy Director of Mental Hygiene Legal Service, (MHLS) Third Judicial Department

Joanne DelRossi, Guardianship Coordinator, Columbia (Coarc)

Shelley VanLare, RN, Quality Improvement Coordinator, The Arc Monroe

Eileen Stewart-Rooney, Guardianship Coordinator, AHRC Nassau Chapter

The Arc New York

Achieve with us.

End-of-Life Decision Making

- Health Care Decisions Act - Article 1750-b (SCPA) – A law outlining the process and legal requirements for any decision to withdraw or withhold "life-sustaining treatment" from individuals with 17-A guardian
- Effective March 2003, but applies to all 17-A guardians regardless of date of decree unless the court order specifically restricts this kind of decision making
- Authorizes a guardian of a person with intellectual and other developmental disabilities to make "any and all health care decisions" aside from those involving life-sustaining treatment

The Arc New York

Achieve with us.

End-of-Life Decision Making

- Health Care Decisions Act - Article 1750-b (SCPA) – A law outlining the process and legal requirements for any decision to withdraw or withhold "life-sustaining treatment" from individuals with 17-A guardian
- Effective March 2003, but applies to all 17-A guardians regardless of date of decree unless the court order specifically restricts this kind of decision making
- Authorizes a guardian of a person with intellectual and other developmental disabilities to make "any and all health care decisions" aside from those involving life-sustaining treatment

The Arc New York

Achieve with us.

End-of-Life Decision Making

- 1750-b is an ethical-legal framework
  - Dignity and uniqueness of every person
  - Possibility and extent of preserving the patient's life
  - Improvement or restoration of patient's health/functioning
  - Relief of suffering
  - Any medical condition and such other concerns and values that a reasonable person in the patient's circumstances would wish to consider
- MOLST is how we fulfill the requirements of that framework
  - Standardized and documented medical order reflecting patient's preferences
  - Not an advanced directive and does not consider future medical conditions
  - Is considered "clear and convincing evidence" of patient's wishes, not just "reasonable knowledge" (a lower legal standard)

The Arc New York

Achieve with us.

What is Life-Sustaining Treatment ("LST")?

- LST Defined
  - "medical treatment, including [CPR] and nutrition and hydration provided by means of medical treatment, which is sustaining life functions and without which, according to reasonable medical judgment, the patient will die within a relatively short period of time"
- Some practical examples *can* include:

CPR (a/k/a DNR)	Surgeries
Intubation/ventilation ("DNI")	IV Fluids
Dialysis	NG, PEG or G-Tubes
Blood transfusions	Use of antibiotics
Chemotherapy	

The Arc New York

Achieve with us.

HCDA Provisions/Protections §1750-b (4)

Capacity Determination:

1. Attending physician and consulting physician/ licensed psychologist must confirm to a reasonable degree of medical certainty that the person lacks capacity to make health care decisions.
2. Attending physician and consulting physician/ licensed psychologist must record the cause and nature of the person's incapacity and its extent and probable duration.

The Arc New York

Achieve with us.

HCDA Provisions/Protections §1750-b (4)(b)(i)

Medical condition must be:

a) terminal condition (means an illness or injury from which there is no recovery, and which reasonably can be expected to cause death within one year), **or**

b) permanent unconsciousness; **or,**

c) a medical condition other than such person's intellectual disability which requires life-sustaining treatment, is irreversible and which will continue indefinitely (chronic illness) **AND** the life-sustaining treatment would impose an **EXTRAORDINARY BURDEN** on the person, in light of:

The Arc New York

Achieve with us.

HCDA Provisions/Protections §1750-b (4)(b)(ii)

- the person's medical condition, other than the person's ID/DD; **AND**
- the expected outcome of the life-sustaining treatment, notwithstanding such person's intellectual disability.

The Arc New York

Achieve with us.

HCDA Provisions/Protections §1750-b (4)(b)(iii)

If the decision is to withdraw or withhold artificially provided nutrition or hydration, doctors ***must also*** determine:

a) there is no reasonable hope of maintaining life; **OR**

b) the artificially provided nutrition or hydration poses an extraordinary burden.

The Arc New York

Achieve with us.

LIABILITY OF GUARDIAN

- Immunity Provided By Statute:

For the guardian when he or she makes a health care decision reasonably and in good faith pursuant to law.

(see SCPA §1750-B)

The Arc New York

Achieve with us.

Assumptions about LST

- 60-70 percent of resuscitations work on TV
- If age 60 or more, actual probability of survival is about 20 percent
- Majority of patients need ventilator afterward
- Feeding tubes can lead to pressure ulcers, distress, use of physical or pharmacological restraints, and pneumonia/aspiration
- Denying artificial hydration or nutrition does not necessarily mean denying food or drink
- Most accurate medical TV show? Scrubs! Chicago Med is number 2. Code Black and ER are tied for third place.

The Arc New York

Achieve with us.

MOLST Checklist Steps

Checklist Order (just follow along)

- 1
- 2
- 3
- 4
- 5
- 6

The Arc New York

Achieve with us.

MOLST Checklist Steps

"Actual Procedure"

- 1: Same as Form
- 2: Same as Form, but only the "specify LST line for now". Decision can be made orally.
- 3: Same as Form
- 4: Same as Form and must match step 2
- 5: Same as Form. Put on notice only. No official notification until ready to make decision. Consider contacting family members if involved.
- Have your committee meeting
- 6: Provide State Office letter, signed, to physician. Complete "decision made in writing" section of step 2
- 7: Physician or hospital completes step 5 and 6

The Arc New York

Achieve with us.

Scenario 1

- 76 yr. old female resident with dementia and dysphagia. She had been receiving tube feedings since she had a stroke.
- She has recently fractured her hip and her cognitive status has worsened. She can only minimally communicate verbally and requires assistance with her daily care routine.
- Guardianship Committee authorizes her move to a nursing home. Her life expectancy is 3-6 months.
- Prior MOLST form indicates CPR should be attempted but no other decisions are indicated. Resident has never had capacity.
- Nursing home staff would like the form to be changed. Can you do so? How?

The Arc New York

Achieve with us.

Scenario 2

- 40 yr. old male resident with end stage MS admitted to hospital with acute respiratory failure via EMS. Had a MOLST but it was not provided to EMS and did not come with to hospital.
- MOLST said no intubation, but because form not available the ED physician intubated.
- Chapter is 17-A guardian but resident has family (they do not reside with resident). Chapter Guardianship Committee members and family both go to hospital.
- Guardianship wants resident extubated. Family does not and attending physician does not.
- What do you do?

The Arc New York

Achieve with us.

Scenario 3

- 76 yr. old female resident with recurring aspiration and sepsis is admitted to the hospital. The hospital treats in several ways including supplemental oxygen and a PEGJ tube. Resident improves slightly.
- Chapter Guardianship and hospital social work staff discuss completing a MOLST with the attending physician, who does is noncommittal for several days. Eventually he participates in the process.
- A MOLST is executed. When MHLS comes to visit the resident in the hospital and to meet with her attending he refuses to stand by the MOLST.
- MHLS decides not to agree to the MOLST order.
- What do you do?

The Arc New York

Achieve with us.

Scenario 4

- 68 yr. old male resident has been treated with dialysis, but his health is failing. The identifiable benefit of dialysis is minimal, if any, though it does have the potential to prolong his life somewhat.
- Patient has other comorbidities, and it is possible he will pass away within 6 months or a year.
- The resident's attending and nephrologist approach the Chapter concerning a MOLST, with dialysis being withdrawn.
- Is dialysis LST in this instance?
- Is it being withdrawn or withheld?

The Arc New York

Achieve with us.

Scenario 4 Continued

- The resident is also on an anti-seizure medication, diuretics, pain control medication, and other medications that support his liver function.
- Should any of these be withdrawn or withheld?
- Are they “comfort care”? If so, which?

The Arc New York

Achieve with us.

Scenario 5

- A 22 yr. old male resident, for which Chapter A is a guardian, fails to gain weight or strength. He eats fairly well but does not have any one life threatening medical issue.
- A DNR/DNI MOLST is put in place because the resident is frail and expected to die within a few months.
- The resident and his guardianship are transferred to Chapter B, where he gains weight and strength due to a custom diet plan.
- Should the MOLST be revisited? Should it remain in place at all?
- What should Chapter A’s Guardianship Committee have done differently?

The Arc New York

Achieve with us.

Scenario 6

- 60 yr. old male resident with profound intellectual disabilities and cerebral palsy
- Admitted to hospital with aspiration pneumonia. On investigation attending finds he has dysphagia and can no longer take in food or fluids orally. Suggests a feeding tube.
- Chapter is Guardian, and refuses to consent to feeding tube. Hospital decides to support this decision because treatment would be an extraordinary burden.
- Tube would require resident be moved to a new facility, be physically restrained, and could lead to complications. However, resident is alert, pain free, responsive, and presents appears fairly happy.
- MOLST form completed that withholds artificial nutrition
- MHLS objects to the withholding

The Arc New York

Achieve with us.

Resources

- **NYSARC Folks: Just Call the State Office!**
- **MOLST pages on CompassionAndSupport.org**: https://www.compassionandsupport.org/index.php/for_professionals/molst_training_center
- **CompassionAndSupport YouTube Channel**: http://www.youtube.com/user/CompassionAndSupport?feature=mhee
- **MOLST Discussions in Hospital & Hospice**: https://youtu.be/gKseJkuuFuk?list=PLCSvowXDKV5LfzLqQGqdQ-n3ocGn8LWZ2
- **MOLST Discussions in Nursing Home**: https://youtu.be/LYAT43hXxwg?list=PLCSvowXDKV5LfzLqQGqdQ-n3ocGn8LWZ2
- **The Arc New York:** Introduction to Medical Aid in Dying Webinar held on 4/4/17 – YouTube Link: https://www.youtube.com/watch?v=efFH2eN18Q0&feature=youtu.be

The Arc New York

Achieve with us.