



## **Guidelines for Types of Minor Patients Appropriate for Thoughtful Medical Orders for Life-Sustaining Treatment (MOLST) Discussions May 2013**

The New York State Department of Health developed instructions and a legal requirements checklist and glossary intended to assist health care professionals in completing the MOLST form with minor patients and minor patients' parents or other legal guardians with authority to make health care decisions for the minor patients. These documents are NOT intended for use with patients with developmental disabilities or for patients with mental illness in a mental hygiene facility.

These guidelines have been developed by pediatric palliative care specialists in New York to help providers understand the types of minor patients who are and are not appropriate for thoughtful MOLST discussions.

### **Pediatric Palliative Care**

The Institute of Medicine defines pediatric palliative care “as a medical discipline that prevents or relieves symptoms produced by a life-threatening medical condition or its treatment, offers help for children with such conditions and their families to live as normally as possible, and provides families with timely and accurate information and support in decision making.”

*“Providing families with timely and accurate information and support in decision-making”* is vital caring for children with serious illness. Sharing this information and working with a family to define goals for care (i.e., what sorts of medical therapies make sense to do or not to do) can be challenging when the discussion involves seriously ill children and their parents.

Discussions with families and children about goals for care should start when a child is diagnosed with a serious illness and continue throughout the course of the child's illness. Goals for care are not static; they may change depending on the nature and trajectory of the illness.

### **MOLST Discussions**

At some point in the course of a child's disease, it is appropriate to document the discussion about goals for care and preferences for life-sustaining treatment on the MOLST form.

MOLST discussions are as much about what we *can* do to help a child as they are about what we can't do. The MOLST form is used to record medical orders for life-sustaining treatment for children when the minor's parent or guardian wishes to avoid or receive any or all life-sustaining treatment. Many children with completed MOLST orders continue to receive disease-targeted therapies, but with some limitations (e.g., the child with relapsed leukemia who wants continued chemotherapy and admissions to the hospital if necessary, but does not want resuscitation in the event of a cardiopulmonary arrest.)

In general, MOLST discussions are not automatically indicated for every child with a life-threatening disease at the time of diagnosis. MOLST may not be appropriate early in the course of a child's illness, particularly if the likelihood of cure is high. However, if the child is

declining, if things are not going as expected, or if a child has a poor prognosis, MOLST discussions would be appropriate sooner rather than later. The timing of the discussion is reflective of a delicate balance between the particular needs of the child and family, the relationship of the pediatrician with the family, the nature of the child's disease and where the child is in the course of his/her disease.

### **MOLST Orders**

MOLST orders completed in accordance with New York law remain valid when the minor patient transitions from one health care setting to another. Non-hospital DNR and MOLST orders must be reviewed and renewed by a physician at least every 90 days. In addition, all MOLST orders must be reviewed consistent with facility policy, and when the minor patient transitions between care settings, when there is a major change in health status, and when the minor patient and/or other medical decision-maker changes his/her mind about treatment. If not reviewed and renewed, MOLST orders are still legal and valid medical orders.

MOLST orders may change over the course of the final phase of a child's illness, consistent with the goals for the child's care. (e.g., the child with relapsed leukemia who no longer wishes to continue chemotherapy and admissions to the hospital, chooses to enroll in hospice and to forego resuscitation and life-sustaining treatment.)

### **Children/Families Appropriate for MOLST Discussions**

MOLST is generally for patients with serious health conditions. Physicians should consider a MOLST discussion if the child:

- Has medical decision-making capacity and wants to avoid or receive life-sustaining treatment.
- Lacks medical decision-making capacity and the child's parent or guardian has already chosen to withhold certain life-sustaining treatment because of their known poor prognosis.
- Might die within the next year.
- Is highly likely to experience clinical decompensation and discussion regarding consideration of life-sustaining treatment is appropriate.

These patients may:

- Want *all* appropriate treatment, including cardiopulmonary resuscitation (CPR).
- Want to avoid *all* life-sustaining treatment.
- Choose to *limit* life-sustaining treatment.
- Want to avoid any attempt to initiate cardiopulmonary resuscitation (CPR) and prefer to Allow Natural Death (DNR order)
- Want to avoid placement of a tube down the throat into the windpipe connected to a breathing machine (intubation) and request a "Do Not Intubate Order" (DNI order).

### **Clinical Examples of Children/Families Appropriate for MOLST Discussions**

The clinical examples are based on the Association for Children with Life-threatening or Terminal Conditions & their Families (ACT) criteria and illustrate when thoughtful MOLST discussions should and should not be considered:

- 1. Life-threatening conditions for which curative treatment may be feasible but can fail. A "goals for care discussion" may be particularly important during phases of prognostic uncertainty and when treatment fails.**

If a child experienced severe head injury as a result of acute trauma in a motor vehicle accident, a thoughtful MOLST discussion is appropriate.

Generally speaking, a child who has relapsed Acute Lymphocytic Leukemia within a year of diagnosis has a poor prognosis, yet cure is possible; thoughtful goals for care and MOLST discussions are appropriate. In contrast, a child with newly diagnosed ALL has an excellent prognosis, and a MOLST discussion is not appropriate at the time of initial diagnosis.

2. **Conditions in which there may be long phases of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities, but premature death is anticipated.**

Young children with cystic fibrosis, Duchenne's muscular dystrophy, or well controlled HIV are not appropriate to have a MOLST discussion, as death may not happen for years. However, if health status and quality of life declines secondary to a serious complication or disease progression (e.g. a patient with cystic fibrosis who is listed for a lung transplant), thoughtful goals for care and MOLST discussions are appropriate.

3. **Progressive conditions without curative treatment options, in which treatment is exclusively palliative and may commonly extend over many years.**

A child with Spinal Muscular Atrophy Type I typically experiences steady decline with a life expectancy of only a few years. Thoughtful MOLST discussions are appropriate earlier in the course of disease.

4. **Conditions with severe neurological disability which may cause weakness and susceptibility to health complications, and may deteriorate unpredictably, but are not considered progressive.**

Children with severe anoxic encephalopathy often have profound patient care needs, including poor airway control. Thoughtful goals for care and MOLST discussions are appropriate.

Not every child with cerebral palsy is appropriate for a thoughtful MOLST discussion. However, complications such as scoliosis, severe restrictive lung disease, recurrent aspiration pneumonias, and feeding intolerance do put the child at risk for frequent hospitalizations, as well as ventilator support. With progressive complications, the condition ultimately can become life-threatening. In summary, as these children grow and develop such complications, MOLST discussions are appropriate.

For a child who has phenylketonuria and is on appropriate diet, thoughtful MOLST discussions are not appropriate.

### **Special Considerations: Emancipated Minors**

Minors, over the age of 16, who are living independently or have a child of their own, may be considered "emancipated." Special considerations and requirements apply to decisions about life-sustaining treatment made by emancipated minors. **Consult with legal counsel concerning MOLST orders for emancipated minors.**

### **Special Considerations: Recommending Health Care Proxies**

In addition, when a child approaches his/her 18<sup>th</sup> birthday and has the ability to decide, it is appropriate to recommend the young adult choose a health care agent and complete a health care proxy.