



## **MOLST for Minor Patients Frequently Asked Questions (FAQs) May 2013**

### **What is MOLST (Medical Orders for Life-Sustaining Treatment)?**

Honoring patient preferences is a critical element in providing quality end-of-life care. Medical Orders for Life-Sustaining Treatment (MOLST) is a program designed to improve the quality of care patients receive at the end of life by translating patient goals for care and preferences into medical orders. MOLST is based on communication between the patient, his or her health care agent or other designated surrogate decision-maker, and health care professionals that ensures shared, informed medical decision-making.

### **What is the DOH-5003 MOLST form?**

To help physicians and other health care providers discuss and convey a patient's wishes regarding cardiopulmonary resuscitation (CPR) and other life-sustaining treatment, the Department of Health has approved a physician order form DOH-5003 MOLST, which can be used statewide by health care practitioners and facilities.

The MOLST form is a bright pink medical order form signed by a New York State licensed physician or a border state physician that tells others the patient's medical orders for life-sustaining treatment. 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.

The MOLST serves as a single document that contains a patient's goals and preferences regarding:

- Resuscitation instructions when the patient has no pulse and/or is not breathing
- Instructions for intubation and mechanical ventilation when the patient has a pulse and the patient is breathing
- Treatment guidelines
- Future hospitalization and transfer
- Artificially administered fluids and nutrition
- Antibiotics
- Other instructions about treatments not listed

Under State law, the MOLST form is the only authorized form in New York State for documenting both nonhospital Do Not Resuscitate (DNR) and Do Not Intubate (DNI) orders. In addition, the form is beneficial to patients and providers as it provides specific medical orders and is recognized and used in a variety of health care settings.

### **Has the DOH-5003 MOLST form been approved for use for minor patients?**

The Department of Health approved the physician order form DOH-5003 MOLST for use with minor patients. MOLST can be used statewide by health care practitioners and facilities.

NYSDOH created a “Legal Requirements Checklist for Minor Patients” with instructions to assist health care professionals in completing the MOLST form with minor patients and their parents or other legal guardians with authority to make health care decisions on his or her behalf. The checklist for minor patients can be found at:  
[http://www.health.ny.gov/professionals/patients/patient\\_rights/molst/docs/checklist\\_minor.pdf](http://www.health.ny.gov/professionals/patients/patient_rights/molst/docs/checklist_minor.pdf).

### **Who is a minor patient?**

“Minor patient” means any person younger than 18 years old who is not married.

### **Who is an emancipated minor?**

An “emancipated minor patient” is a minor patient, over the age of 16, who is living independently or has a child of their own. “Over the age of 16” means the minor patient is at least 16 and younger than 18 years of age.

### **What type of minor patient should have a MOLST form?**

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).

### **What are some clinical examples of children who may be appropriate for a MOLST discussion?**

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.

### **When in the course of the child's illness might it be appropriate to discuss completing a MOLST form?**

In general, MOLST discussions are not automatically indicated for every child with a life-threatening disease at the time of diagnosis. MOLST is not 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.

### **How is a MOLST form completed for a minor patient?**

The MOLST form must be completed based on the patient's current medical condition, values, wishes, and informed consent by the minor patient who has decision-making capacity or his/her authorized decision-maker, i.e. the minor's parent, guardian or §1750-b Surrogate.

Completion of the MOLST begins with a conversation or a series of conversations between the minor patient who has decision-making capacity or the authorized decision-maker and a qualified, trained health care professional that defines the patient's goals for care, reviews possible treatment options on the entire MOLST form, and ensures shared, informed medical decision-making. The conversation should be documented in the medical record. The MOLST orders cannot be issued without the consent of the patient or other medical decision-maker.

Although the conversation(s) about goals and treatment options may be initiated by any qualified and trained health care professional, a licensed physician must always, at a minimum: (i) confer with the patient or authorized decision-maker about the patient's diagnosis, prognosis, goals for care, treatment preferences, and consent by the appropriate decision-maker, and (ii) sign the orders derived from that discussion. If the physician is licensed in a border state, the physician must insert the abbreviation for the state in which he/she is licensed, along with the license number.

### **How much of the form should be completed for a minor patient?**

Completion of both the first and second pages of the MOLST form is strongly encouraged. However, the minor patient who has medical decision-making capacity or decision-maker (i.e. the parent or legal guardian) may not be physically or emotionally prepared to reach a decision concerning every treatment option on the form in a single meeting.

Completion of only page 1 of the MOLST form (concerning CPR/DNR) is permissible, and page 2 (Section E) may be completed at a later time.

If a minor patient who has medical decision-making capacity or decision-maker can reach a decision on one or more treatment options, but not others, on page 2, the physician should cross out the portion of the form with the treatment option(s) for which there is no decision and write "Decision Deferred" next to those treatment option(s). If the patient or decision-maker reaches a decision concerning that treatment option(s) at a later time, a new form must be completed and signed by a physician, indicating all of the minor patient's or decision-maker's decisions.

The Department has developed Legal Requirements Checklists to assist providers in completing the forms with minor patients and/or their authorized medical decision-makers in various settings. The checklists are available at: [http://www.health.ny.gov/professionals/patients/patient\\_rights/molst/](http://www.health.ny.gov/professionals/patients/patient_rights/molst/)

### **What are the standards by which a parent/guardian must make a decision on the MOLST?**

The parent's or legal guardian's decision must be patient-centered, in accordance with the patient's wishes, including the patient's religious and moral beliefs; or if the patient's wishes are not reasonably known and cannot with reasonable diligence be ascertained, in accordance with the patient's best interests. The parent's or legal guardian's assessment is based on the patient's wishes and best interests, not the parent's or guardian's, and includes consideration of:

- the dignity and uniqueness of every person;
- the possibility and extent of preserving the patient's life;
- the preservation, improvement or restoration of the patient's health or functioning;
- the relief of the patient's suffering; and
- any medical condition and such other concerns and values as a reasonable person in the patient's circumstances would wish to consider.

### **When should the child be included in a MOLST discussion?**

If a minor has the ability to understand the MOLST discussion, the child should be included in the discussion.

### **Can the minor patient defer medical decision-making to the minor patient's parents or other legal guardians?**

When the minor patient has the capacity to make medical decisions as part of the MOLST discussion, the minor patient has the right to defer the medical decision-making to the parents or guardians.

### **What if the minor patient has medical decision-making capacity and disagrees with one or both parents' decisions about limiting life-sustaining treatment?**

If a minor has decision-making capacity, then a parent's decision to withhold or withdraw life-sustaining treatment may not be implemented without the minor's consent. The minor must agree and the decision cannot go forward without the minor's approval if the minor shows an ability to understand and appreciate the treatment decisions on the MOLST.

If there is a lack of consensus (e.g. if the minor patient wants to stop and the parents want to continue), efforts should be made to resolve it informally if possible (e.g., through conflict resolution process, mediation, ethics consultation or the hospital ethics process). If efforts fail, the matter should be referred to the Ethics Review Committee. In the meantime, the MOLST cannot be completed until the conflict is resolved.

### **What are the clinical standards a physician must use for DNR orders and medical orders to withhold or withdraw life-sustaining treatment and thus, complete the MOLST?**

The attending physician, with the independent concurrence of another physician, to a reasonable degree of medical certainty and in accord with accepted medical standards, must agree that the parent or legal guardian's decision meets one of two clinical standards:

1. Treatment would be an extraordinary burden to the patient and 1) the patient has an illness or injury which can be expected to cause death within six months, whether or not treatment is provided; or 2) the patient is permanently unconscious.
2. The provision of treatment would involve such pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances; and the patient has an irreversible or incurable condition.

If clinical standard 2 is met, additional **special requirements** exist unless the patient is in hospice.

- In a **hospital**, when the medical order involves the withdrawal or withholding of artificial nutrition or hydration, and the attending physician objects to the order, the ethics review committee (including a physician who is not directly responsible for the patient's care) or an appropriate court must determine that the medical order meets the patient-centered and clinical standards.
- In a **nursing home** or in the community, for MOLST orders other than a DNR order, an ethics review committee, (including at least one physician who is not directly responsible for the patient's care) or an appropriate court must determine that the orders meet the patient-centered and clinical standards.

**If the physician is having a thoughtful MOLST discussion based on goals for care *in the home or office* with parents of a terminally ill child and they wish for the child to not receive artificial fluids and nutrition, when can the decision be included on the MOLST form?**

If the terminally ill child resides in the community, the attending physician must agree that the parent or legal guardian's decision meets one of two clinical standards and a concurrent determination must be made by an independent physician:

1. Treatment would be an extraordinary burden to the patient and 1) the patient has an illness or injury which can be expected to cause death within six months, whether or not treatment is provided; or 2) the patient is permanently unconscious.
2. The provision of treatment would involve such pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances; and the patient has an irreversible or incurable condition.

If clinical standard 2 is met, additional **special requirements** exist unless the patient is in hospice. An ethics review committee, (including at least one physician who is not directly responsible for the patient's care) or an appropriate court must determine that the orders meet the patient-centered and clinical standards. The MOLST cannot be completed until the special requirement is met.

**What if my patient is  $\geq 18$  years of age and his/her parents do not want me to discuss MOLST orders (e.g. DNR/DNI) with him/her. Can the MOLST form be completed based on the parents' wishes?**

No. A patient who is  $\geq 18$  years of age and who has medical decision-making capacity must consent to any limitations placed on his/her care. Further, a patient who is  $\geq 18$  years of age has the right to choose a health care agent, including his/her parent. A patient who is  $\geq 18$  years of age can defer medical decision-making to his/her health care agent.

**What if both parents have legal guardianship and they do not agree with each other on limiting life-sustaining treatment?**

If there is a dispute, efforts should be made to resolve it informally if possible (e.g., through conflict resolution process, mediation, ethics consultation or the hospital ethics process). If efforts fail, the matter should be referred to the Ethics Review Committee. In the meantime, the MOLST cannot be completed until the conflict is resolved.

**If a parent or guardian of a minor patient has made a decision to withhold or withdraw life-sustaining treatment, must an attending notify a parent or guardian who has not been informed of the decision, including a non-custodial parent or guardian?**

Where a parent or guardian of a minor patient has made a decision to withhold or withdraw life-sustaining treatment and an attending physician has reason to believe that the minor patient has a parent or guardian who has not been informed of the decision, including a non-custodial parent or guardian, an attending physician or someone acting on his or her behalf, shall make reasonable efforts to determine if the uninformed parent or guardian has maintained substantial and continuous contact with the minor and, if so, shall make diligent efforts to notify that parent or guardian prior to implementing the decision.

**What are the decision-making standards a physician must use for DNR orders and medical orders to withhold or withdraw life-sustaining treatment and thus, complete the MOLST for an emancipated minor patient?**

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.**