

MOLST: New York State's Medical Orders to Honor the Wishes of a Seriously Ill Patient

By Judith D. Grimaldi and Tammy R. Lawlor

An 80-year old woman with a terminal illness had made clear to all those who knew her that she wanted to remain in her home and did not want any life-sustaining treatment in the event something occurred. The frail woman collapsed, her aide instinctively, and as trained, called 911, and EMS responded to her residence. Fortunately, she had her bright pink MOLST form hanging on her refrigerator. The form signed by her treating physician weeks before in consultation with her and her family stated that she did not want to be resuscitated and not to do CPR. The EMS responder immediately searched for this pink form upon entering the residence. He had been informed and trained on carrying out the MOLST medical orders and knew to look at the preferred location on the refrigerator. The responder did not revive the woman, because he reviewed said form for the medical directives. His actions honored her wishes as he had the medical orders authorized by her licensed physician. It was unnecessary for the EMS responder to contact the woman's health care agent, to conduct CPR or have her transported to the hospital awaiting the health care agent's response or, worse, provide unwanted emergency treatment and resuscitation.

MOLST is the newest addition to the end-of-life medical directives now available to our clients and to which we as elder law attorneys will be exposed. MOLST means Medical Order for Life Sustaining Treatment. As such it is our responsibility to educate and inform our clients as to the importance of the MOLST form. Although we cannot complete said forms with our client, as it is an active medical order, we can discuss said form and advise him or her of its potential value. MOLST gives our clients the power to make their wishes known, while providing the health care professionals with the authority to carry out their wishes using a medical directive. It is an agreement between a doctor and patient as a result of a proscribed decision-making process. This does not require further conversations with the patient or their health care agent at the time of the health emergency or need for treatment. It is an actionable order to be followed because it is an accurate reflection of the patient's wishes. The immediacy of MOLST as a medical order is both its strength and its possible weakness. Therefore training, education and care must accompany the implementation of MOLST to ensure it truly reflects the patient's wishes and is the result of careful consideration of all parties involved. As a medical order it is intended to be used by those who have serious health conditions and are nearing the end of life. This form is completed by a health care professional based upon the patient's

wishes for life-sustaining treatment. The patient and a medical doctor licensed in the State of New York must sign the MOLST form. The form is on bright pink paper so that it can be easily identified in case of an emergency. The MOLST/DNR is not hospital or admission specific, but can be transferred from one health care setting or care level to another. The original MOLST form should travel with the patient to different care settings.

Governor Pataki signed the MOLST bill (A.8892, S.5785) establishing this pilot MOLST program on October 11, 2005 which was initiated in Monroe and Onondaga Counties. Said bill allowed for the use of the MOLST form in lieu of the New York State Nonhospital Do Not Resuscitate (DNR) form.

Governor Pataki established a carve-out for the Office of Mental Health (OMH) and Office of Mental Retardation and Developmental Disabilities (OMRDD). Under the Surrogate's Court Procedure Act § 1750-a and § 1750-b, individuals with mental illness and/or developmental disabilities with capacity are allowed to complete a MOLST form.

A Chapter Amendment (A.9479, S.6365) signed by Governor Pataki on July 26, 2006 permitted EMS to honor Do Not Intubate (DNI) instructions prior to full cardiopulmonary arrest. Use of MOLST was passed by the NYS legislature in June 2008, becoming statewide and permanent when Governor Paterson signed it into law on July 8, 2008 in the Public Health Law § 2977 (13). This action amended the public health law and allowed the MOLST form to be used in community and hospital settings and EMS services across New York State.

The MOLST tool was created by a workgroup of the Community-Wide End of Life/Palliative Care Initiative in Rochester, New York and was incorporated into the recently passed statewide program. They implemented an 8-Step MOLST Protocol to encourage and foster discussions between terminal patients, their families and their physicians. It reinforces the importance of treating these patients with dignity, respect and compassion. It provides the families with the support they need and deserve. The workgroup wanted to strongly encourage those with life-threatening illness to embrace the process of life and death. It is extremely important for the patients to engage in certain thought processes and discussions to appropriately reach decisions that they are comfortable with and that they can be sure will be carried out. With the 8-Step Protocol, it allows the individual to plan ahead, know their choices, make sound decisions and share their wishes with their family and physicians.

The MOLST form cannot be changed if the patient or doctor does not like the form. The form is consistent with New York State Law and conforms to New York State Public Health Law. The original MOLST forms underwent an extensive review process with the New York State Department of Health (NYSDOH) in 2005. The current MOLST form revised in August 2008 includes the amendment to the Public Health Law signed in July 2008.

There is a primary MOLST form and two supplemental forms available. The basic form is the "MOLST for DNR and other Life Sustaining Treatments" (see attached). The types of treatment that are included in the form are comfort care; limited medical intervention; hospitalizations and transfers; artificial nutrition and hydration; and/or antibiotics. There is sufficient room to describe the specific wishes of the individual.

One of the supplemental forms is the "MOLST for MINORS" which is completed in consultation with the parent or legal guardian. There are specific instructions regarding efforts to contact the noncustodial parent. The second supplemental form is the "MOLST for ADULTS" which is for adults who lack capacity. This form requires the physician to determine who the proper surrogate to make decisions is, and it requires the surrogate to sign before witnesses.

The MOLST is divided into sections to address each health care directive separately. Section A provides for resuscitation instructions and is equivalent to the Hospital DNR. If Section A is **not** completed, the patient will be revived. Section B addresses DNR as it applies to cardiac arrest (CPR). Section E provides for the ability to set trial periods for treatment. For example, trial periods for artificial feeding, intubations and ventilation and methods of pain relief and comfort care are provided in an easily understood method. MOLST can also limit future hospitalizations to instances when pain or severe symptoms cannot be controlled at home or in a long-term-care facility. Additional instructions can also be included to address treatment decisions concerning such care as: dialysis, implantable defibrillators and the duration of time-limited trials. The form is intended to be periodically reviewed and renewed based upon any changes in the current medical condition. An entire section F is dedicated to changes to the MOLST form. The entire MOLST form should be reviewed and renewed by a physician when the patient is transferred from one facility to another; there is a substantial change in the person's health status; or the patient's/resident's treatment preferences change.

Certain deadlines have been established outlining when the physician should review the form according to the patient's treatment setting:

- Hospital: at least every seven (7) days
- Nursing Home/Skilled Nursing facility: at least every sixty (60) days

- Nonhospital/community setting: at least every ninety (90) days

When completing the MOLST form, the issue of capacity may arise and the physician must make a determination as to capacity. Under NYS Public Health Law, before using a DNR order, a determination of capacity to consent to a DNR order must be made. For a patient who lacks decision-making capacity and does not have a valid DNR order executed, a doctor must first document the cause, nature and extent of the lack of capacity. With patients who lack capacity due to "mild dementia," the determination must be affirmed by a concurring physician before issuing a DNR order. The concurring physician does not need to be board certified or board eligible in psychiatry. Other types of patients who may lack decision-making capacity are individuals with mental retardation, developmental disabilities, head injury, delirium or mental illness. For those individuals with mental retardation or developmental disability, the concurring opinion must be provided by a physician or psychologist with special experience or training in the field of developmental disabilities. If the individual lacks capacity because of mental illness, the concurring physician must be board certified in psychiatry.

If the individual had capacity when the original MOLST form was completed, but no longer has capacity at renewal, the health care professional must rely on information in the medical record. The reviewer will seek documentation that the patient fully participated in the prior conversations which created the order. There will be a presumption that the patient had decisional capacity at the time of the MOLST completion. The Health Care Agent, if available, can also renew the MOLST with the physician and affirm the patient's prior decisions. Health care professionals are directed to take the following steps before using MOLST when the patient cannot verify the directions given in the MOLST form:

- Assess the patient's capacity at the time of signing the form.
- Review admission or transfer papers for evidence of documentation of the conversations at the original execution of the MOLST form.
- If no documentation is available, verify information through the physician who completed the MOLST form, as the physician's license and phone number are on the form.

In the event changes are not able to be made directly on the MOLST form, verbal orders are acceptable if followed later by a physician signature and documentation. Hospitals can rely solely on the MOLST form to withhold and discontinue life-sustaining treatments. The form clearly states to follow these orders first, and then contact the physician. The state's basis for the su-

perior weight given to MOLST over other directives is based on the fact that MOLST's creation was preceded by thoughtful prior discussions between the patient and the health care professionals. It is presumed that the MOLST discussions were shared with the family and the appointed surrogate. The resulting form is based on informed medical decision-making and documented patient preferences.

The MOLST form is not intended to replace traditional advance directives including the Health Care Proxy and Living Will. A Health Care Proxy and Living Will are for all adults over the age of 18. These documents apply only when the patient is unable to make his or her own health care decisions. Said documents are signed by the patient and witnessed by two individuals; however, a physician does not need to be involved in the completion of said documents. These documents are future directives and can be dormant but in existence for many years. In the alternative, MOLST is intended to apply immediately for treatment of a serious illness. MOLST is not conditional on losing decision-making capacity but is an active consent to a present situation.

In signing the legislation, Governor Paterson said, "People should be allowed as much say in their end-of-life care as they would have at any other time. This bill will allow many people who are critically ill to make enduring decisions on the care they will receive. These will be difficult decisions for every person to make, but they should have the freedom to make them." The Governor was supported by State Health Commissioner Richard F. Daines, M.D.: "I congratulate Governor Paterson on signing this bill. This will give patients more choices for end-of-life care. It expands patients' instructions beyond a do-not-resuscitate order into areas of intubation and medication, which many end-stage patients would like to control for themselves as much as possible."

As with any new form, there is bound to be some institutional hesitancy and confusion. Dr. Patricia Bomba, the Medical Director of BC/BS Excellus in Rochester, NY, who spearheaded the introduction of MOLST through the Community-Wide End of Life Palliative Care Initiative in Monroe and Onondaga Counties, is working on trainings statewide to introduce the proper use and benefits of MOLST. Dr. Bomba states, "We are encouraging implementation of MOLST through use of our comprehensive website with over 40 detailed FAQs and through a series of all day MOLST conferences for hundreds of New York State professionals. We are trying to ensure that everyone across New York State has access to the MOLST program when needed."

Elder law practitioners will need to become familiar with the form and the projected use in home, nursing homes, home care agencies, and hospitals for individuals who are facing end-of-life issues. As attorneys,

it is our responsibility to encourage our clients to engage in these discussions with their family and physicians. Extensive training materials and information are readily available on the MOLST website developed by Dr. Bomba at www.CompassionandSupport.org. This site provides insightful scenarios to consider which will promote productive conversations about care choices between our clients, their families and physicians.

The concern in the elder law community is that the documentation needed to keep the MOLST accurate is too ambitious for the present chaotic medical system. The fear is that the forms will be completed as routine admission forms and not as a stimulus to necessary end-of-life decision making. Many patients arrive at nursing homes with inadequate documentation on their primary condition and general medical orders. It seems unlikely that the MOLST will survive the transfer from hospital to nursing home any better. Families often report that the patient is discharged to the facility with bare bones medical information and the family often must report the history. They are often asked by the nursing home and rehabilitation facility to sort out the medications and care issues. It is optimistic that the transferring of detailed documentation of MOLST conversations will routinely occur. Yet, it is a goal worth striving for; but we should be prepared for some failures. Thus, our clients should be warned that MOLST may need to be completed again in the nursing home setting and renewed if the end-of-life order is central to the care needed at the new facility. Many people are concerned that the MOLST will invalidate or undermine the Health Care Proxy; however, this is unfounded in that the agent is expected to be involved in this order and will be required to consent if the patient is unable to do so.

MOLST can be a welcomed source of end-of-life planning for the individual who faces a terminal illness or end-stage chronic illness where there is no hope of improvement. MOLST, when executed with the care and support of the treating physician, can ensure dignity and efficiency in the end of life treatment. The immediacy of the "Medical Order" can deliver treatment in the manner preferred and eliminate the negotiations, angst and often uncertainty which can accompany this stage of care. Copies of the MOLST form are available at www.CompassionandSupport.org. As attorneys we do not have the power to complete said forms, but we do have the power to inform and suggest that our clients engage in the process with their physicians. Look for the formal introduction of MOLST statewide as part of National HealthCare Decisions Day set for April 16, 2009.

Judith D. Grimaldi and Tammy R. Lawlor are Co-Chairs of NYSBA's Elder Law Section's Health Care Issues Committee.