Health Law Journal

A publication of the Health Law Section of the New York State Bar Association



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Medical Orders for Life-Sustaining Treatment (MOLST): A Paradigm Shift in Advance Care Planning

By Patricia A. Bomba, M.D., F.A.C.P.

Patient preferences for care at the end-of-life are not consistently followed, despite the presence of legal documents completed in accordance with state law. Clinical scenarios as illustrated below regularly unfold where the focus of conversation is purely on choice of interventions rather than a person-centered, goal-based discussion.

Patient is an 80-year-old retired successful businessman, former semi-professional athlete who now resides in a nursing home. He has a 25-year history of Parkinson's disease currently in the final stages, associated with dementia for the past ten years and a host of other medical problems. Presently he is totally dependent in all activities of daily living, rarely "recognizes" his wife but does not recognize other family members. Two years ago he was moved from a private to semi-private room and became delirious. The delirium lasted several months. He has a properly executed Health Care Proxy and Living Will completed when he had decision-making capacity. His wife, his designated Agent, has intact decision-making capacity. The nursing home staff raises the issue of a Do Not Resuscitate (DNR) order. While his wife realizes this was her husband's wish, both she and her son are emotionally conflicted. His daughter believes her father's wishes should be honored, regardless of personal feelings. A family meeting is held to focus on goals for future care. All are in agreement that the patient's quality of life is the primary goal. Further discussion reveals that the family does not understand what cardiopulmonary resuscitation (CPR) entails or the anticipated poor survival rate for patients with complex medical conditions and frailty. The son's perception hinges on a comment from the evening shift nurse, "Your father has a strong heart." When provided with the medical evidence base for CPR in the face of the current clinical scenario and empathetically acknowledging their emotions, the family is prepared to make a decision consistent with the patient's previously expressed wishes and accept a natural death, unattached to life support. Through focusing on the patient's quality of life as the goal for care, they are open to discussion of additional lifesustaining treatment and potential hospital transfer.

Recognizing and accepting death as inevitable helps one to appreciate life fully, to live in the present moment and to help others plan for the unavoidable. An individual has the right to make health care decisions, a right that persists in the final chapter of life. When our final chapter is written, will our wishes about the type of care we want to receive be followed? Will anyone know what we want? Have we chosen the most effective surrogate decision—maker, shared our values and beliefs and completed our own Health Care Proxy? Have we spoken with our agents, family, loved ones, physicians and health care providers? Is our document accessible and reviewed on a regular basis? Will they follow our wishes?

"An individual has the right to make health care decisions, a right that persists in the final chapter of life. When our final chapter is written, will our wishes about the type of care we want to receive be followed?"

Do the terms "terminal" and "irreversible" provide sufficient clarity for health care professionals? What does the person with Alzheimer's disease prefer when the final phase of the disease arrives and the desire for food diminishes, swallowing problems lead to aspiration, pneumonia and fever? Without antecedent focused discussion, how does the health care professional proceed in the face of a terminal illness with a superimposed potentially reversible pneumonia?

If you had an advanced chronic condition or serious illness and would likely die in the next year, would you want to know? Would this impact your goals for care? Would you focus on the quantity or quality of your life? Would this impact the treatment decisions you make? What would you do differently to ensure the type of care you want to receive while you still have intact decisional capacity?

Summary

Honoring patient preferences is critical to providing quality end-of-life care, consistent with the individual's values and beliefs, based on informed medical decision-making and evidence-based medicine. To enable physicians and other health care professionals to discuss and convey wishes of patients with advanced chronic or

serious illness, the Medical Orders for Life-Sustaining **Treatment (MOLST)** form (Appendix A on pages 47-50 of this issue) was created. Based on Oregon's Physician Orders for Life-Sustaining Treatment (POLST), MOLST is a physician order form used to record actionable medical orders pertaining to life-sustaining treatments including cardiopulmonary resuscitation (CPR). The MOLST form improves the communication of patient wishes by centralizing all life-sustaining treatment orders on one bright pink form that is easily recognized in case of an emergency. Once completed, the MOLST form accompanies the patient across care settings. Approved by the New York State Department of Health (NYSDOH) for institutional use, MOLST is spreading to hospitals, long-term care facilities, hospice agencies and home care agencies throughout the state.

Although MOLST can now be used *in facilities*, the ultimate goal is to also use MOLST *in the community* and to improve EMS personnel's ability to treat according to patient wishes. Governor Pataki signed the MOLST bill (A.8892, S.5785) establishing a pilot of the MOLST program in Monroe and Onondaga Counties on October 11, 2005. This bill allows for the use of the MOLST form *in lieu of* the New York State Nonhospital Do Not Resuscitate (DNR) form. A Chapter Amendment (A.9479, S.6365), signed by Governor Pataki on July 26, 2006, permits EMS to honor Do Not Intubate (DNI) instructions prior to full cardiopulmonary arrest in Monroe and Onondaga Counties during the MOLST Pilot and provides a carve out for persons with mental retardation and developmental disabilities *without* capacity.

Introduction

Advances in health care and changing demographics have led to an aging population facing increasingly complex end-of-life care. Life expectancy and prevalence of chronic disease has increased. Adding to the complexity are increased comorbidities and frailty with advancing age, changing families, health care systems, society and marketplace demands. Finally, and perhaps most importantly, we exist in a culture where death is viewed as "optional."

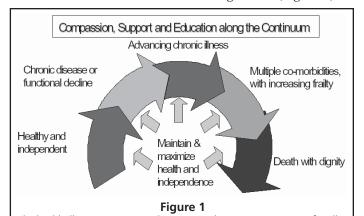
In the midst of these evolving realities, it is critically important to focus on the patients' perspective of quality end-of-life care. Singer and colleagues identified and described the patients' perspective of quality end-of-life care as receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving the burden on loved ones and strengthening the relationship with loved ones. McGraw and colleagues added respecting the uniqueness of individual, providing an appropriate environment, addressing spiritual issues, recognizing cultural diversity, and effective communication between the dying person, family and professionals.²

Unfortunately, humane care for the dying is a social obligation not adequately met in our country, including New York State. Too often, death is considered a medical failure rather than the inevitable last chapter of life. As a result, many people approach death fearing abandonment, profound suffering of self and family and a protracted, and an over-treated ending. Their fears are not unsubstantiated. Life-sustaining procedures are frequently administered in direct contradiction to the patient's wishes. Despite the growing proclivity to administer lifesustaining treatments, research indicates that increases in interventions have not reduced mortality rates.³ In many cases, life-sustaining treatments only prolonged the dying process. Reducing unwanted, unnecessary and futile interventions at end-of-life will realign the intensity of care more with patient preferences without adversely impacting mortality rates.

Currently, conversations about death are too often avoided until a crisis occurs, resulting in inadequate Advance Care Planning and patient preferences not being known or honored. For example, more than 70 percent of surveyed Americans indicated that they wish to die at home. Yet, only 25% of Americans die in their home while the other 75% die in institutions (i.e., hospitals, nursing homes). In place since the Patient Self-Determination Act (PSDA) passed in 1991, the current system of communicating end-of-life care wishes solely using traditional advance directives, such as the Health Care Proxy and Living Will, has proven insufficient.

Traditional Advance Directives

Anyone can face sudden, unexpected life-limiting illness or injury. Thus, advance care planning is appropriate for all adults 18 years of age and older, not only the subset of Americans with life-limiting illness (Figure 1).



The health-illness continuum. Advance care planning is appropriate for all adults 18 years of age and older, not only the subset of Americans with life-limiting illness. People who are healthy and independent can face sudden, unexpected life-limiting illness or injury. These individuals should complete traditional advance directives. Individuals with advancing disease benefit from more intensive discussion while they have capacity and should complete actionable medical orders like the MOLST form. Thus, advance care planning should be incorporated along the entire continuum of care.

The process determines future medical care preferences if decisional capacity is lost. Advance care planning focuses on conversation, selection of a trusted surrogate to represent the patient when the capacity to represent oneself is lost, and clarification of values and beliefs. The result is accessible legal documents completed in accordance with state law. Advance care planning helps a patient to maintain control, achieve peace of mind and is an important step to assuring that wishes are honored. Absence of legal documents can result in situations illustrated by Karen Ann Quinlan, Nancy Cruzan and Terri Schiavo.

When advance care planning occurs and is done well, traditional directives like the Health Care Proxy are completed and conversation occurs with family, loved ones, physician and other trusted individuals. A Health Care Proxy applies only when decision-making capacity is lost. Patient goals guide care and should continue to do so even when the patient loses capacity. Documents are regularly updated and are available in an emergency.

Too often, advance care planning does not occur and the resulting conflict manifests in a variety of ways. The Agent and family may disagree with the physician assessment. Alternately, the Agent and physician may agree while another family disagrees and interferes. There may be a disagreement regarding the goals for care, with the Agent and family focused on quality of life while the physician recommends extending quantity of life. There may be disagreement among physicians. The clinical situation becomes more complicated when a patient lacks capacity and no Agent or family exists. Complicating matters, the language used frequently results in unintended consequences.

Unfortunately, advance directives are not widely used. The advance directive completion rate in the United States has not significantly increased since the passage of the Patient Self-Determination Act. In 1991, the year the PSDA passed, 75% of Americans approved of a living will, yet only 20% had some form of advance directives.⁵ A 2002 study showed no improvement in the advance directives completion rate. The completion rate remained at 15-20%.6 Completion rates were no better for higher risk individuals. Only 20% of nursing home residents had any form of advance directive. A November 2005 poll by the Pew Research Center for the People and the Press revealed Americans are increasingly likely to plan for future health care. A recent poll performed after the Schiavo case unfolded before the nation indicated 29% of Americans have advance directives.8

Moreover, even if advance care planning occurs traditional advance directives are often unavailable, overlooked, ignored or not communicated once the individual enters the health care system. In spite of these potential drawbacks, traditional advance directives, notably the

New York State Health Care Proxy, retain a critical role in identifying a trusted individual to serve as the appropriate surrogate decision maker for patients if they lose capacity, particularly in the absence of surrogacy laws aside from cardiopulmonary resuscitation.

Medical Orders for Life-Sustaining Treatment (MOLST)

To complement the use of traditional advance directives and facilitate the communication of medical orders impacting end-of-life care for patients with advanced chronic or serious illness, the Medical Orders for Life-Sustaining Treatment (MOLST) program was created. In contrast to a Health Care Proxy, the MOLST applies right now and is *not* conditional on losing decision-making capacity. The MOLST program is based on the belief that individuals have the right to make their own health care decisions, including decisions about life-sustaining treatments, describe these wishes to health care providers and to receive comfort care while wishes are being honored. This community-wide program provides a framework for facilitating the communication and documentation of an individual's goals and wishes regarding life-sustaining treatments across care settings, while educating the health care system and its providers to be responsive to patient

The aim of MOLST is to express patients' treatment goals as actionable medical orders that are based on communication with patients and/or surrogates, using the informed consent process. MOLST brings together multiple professionals from across the health care system to meet the goals of patients. The process results in completion of the MOLST form (Appendix A) which may be used either to limit medical interventions or to clarify a request for all medically indicated treatments including cardiopulmonary resuscitation (CPR). The form provides explicit direction about resuscitation status if the patient is pulseless and apneic. It also includes directions about other types of intervention that the patient may or may not want. For example, decisions about transport, ICU care, antibiotics, artificial nutrition, etc. The form accompanies the patient, and is transferable and applicable across care settings (i.e., long-term care, EMS, hospital). It is uniquely identifiable, standardized, and a uniform bright pink color. MOLST should be reviewed and renewed periodically as required by New York State and Federal laws or regulations, if the individual's preferences change, if the individual's health status changes, or if the individual is transferred to another care setting.

The process includes training of health care professionals across the continuum of care about the goals of the program, implementation, use of the form and a plan for ongoing monitoring of the program.

Development of MOLST, a POLST Paradigm

The Community-wide End-of-life/Palliative Care Initiative, a Rochester, New York-based initiative aimed at improving end-of-life care in New York, developed the original MOLST form in 2003. When initially formed in 2001, the Initiative set forth community goals to be developed locally and shared regionally. These included:

- 1. All adults 18 years of age and older should have an opportunity to complete a traditional Advance Directive.
- The health care community should adopt a comprehensive Advance Directive that all area practitioners and institutions will honor.
- Patients should be referred to Hospice earlier so that the social, spiritual and psychological components of suffering can be addressed.
- 4. Practitioners and Health Care Facilities should establish comprehensive pain assessment and treatment standards at every site of care.
- 5. Health Care Institutions should be encouraged to set performance goals and track basic statistics regarding end-of-life care.

A review of the literature for preferred practices revealed the *Physician Orders for Life-Sustaining Treatment (POLST)* program developed in Oregon in the early-mid 1990s. A decade of research in the state of Oregon has proven that the POLST program more accurately conveys end-of-life preferences that are more likely followed by medical professionals. ¹⁰ The POLST program has been a key vehicle in Oregon's successful efforts to increase the effectiveness of advance care planning and decrease unwanted hospitalizations at the end of life. ¹¹

MOLST was developed to incorporate New York State law. The MOLST Program was designed to:

- 1. Align medical orders with patient wishes.
- 2. Document the patient's treatment preferences regarding life-sustaining treatments including cardiopulmonary resuscitation (CPR), intubation and mechanical ventilation.
- 3. Communicate patient wishes regarding care across health care settings.
- 4. Improve emergency medical services (EMS) personnel's ability to provide emergency treatment according to the individual's wishes.
- Reduce repetitive documentation while complying with New York State law and the federal Patient Self-Determination Act.

In collaboration with the New York State Department of Health, Excellus BlueCross Blue Shield revised the

MOLST form in 2005. The revised MOLST is consistent with state law and approved for use as an inpatient Do Not Resuscitate form in all health care facilities in New York State.

POLST is spreading across the country as part of the National POLST Paradigm Initiative. New York State's MOLST Program is one of six endorsed POLST Paradigm Programs. To learn more about the POLST Paradigm Initiative and other states that are replicating this goal-based paradigm, see www.polst.org. States with endorsed programs may vary in name and format but share essential core elements, as exemplified by New York State's MOLST.

Appropriate Use of MOLST

Predicting and outlining guidance for all possible clinical scenarios is difficult. Advance directives are rarely sufficiently precise to dictate patient preferences in a specific situation as disease progresses. Thus, for a patient with advanced chronic illness or a serious health condition, conversion of patient-centered treatment goals into actionable medical orders while the patient retains capacity provides a more effective means of communicating and ensuring patient preferences are honored than traditional advance directives. Anyone residing in a longterm care facility or anyone eligible for long-term care but who chooses to age in place at home is an appropriate candidate to complete the MOLST. Completion of the form is also important for any patient who may die in the next year, including patients with metastatic cancer, endstage cardiac or pulmonary disease or advanced dementia. Additional appropriate candidates include those who wish to limit certain interventions or choose to allow and embrace natural death, unattached to life support, and choose a DNR order.

American Bar Association expert Charlie Sabatino points out: "The message behind the term 'do not resuscitate' is predominantly negative, suggesting an absence of treatment and care. The reality is that comfort care and palliative care are affirmative and, for these patients, more appropriate interventions." ¹²

Physicians tend to overestimate the likelihood of survival of in-hospital cardiopulmonary arrests to hospital discharge. The literature reports an average survival rate of 15%. At least 44% of the survivors have significant decline in functional status at the time of discharge. Chronic illness, more than age, determines prognosis in the elderly; elderly with chronic illness have an average survival rate of less than 5%. For those with advanced illness, survival rates are often less than 1%.

Improved survival rates with good functional recovery are reported with the duration of CPR shorter than 5 minutes and CPR occurring in the ICU. 14 Poor outcomes at all sites of care are associated with unwitnessed arrest,

asystole, electrical-mechanical dissociation, greater than 15 minutes of cardiopulmonary resuscitation, metastatic cancer, multiple comorbidities and sepsis. Patients and families have significant functional health illiteracy with regards to life-sustaining treatment, adding to the burdens of medical decision-making. Studies have shown that physicians speak to patients 75% of the time, often using medical jargon. Further studies reveal that after discussions related to cardiopulmonary resuscitation, 66% of individuals did not know that many patients need mechanical ventilation after resuscitation, 37% thought ventilated patients could talk and 20% thought ventilators were oxygen tanks. 16

The survival rate misconceptions are likely further complicated by the fact that 67% of resuscitations are successful on television. ¹⁷ Actually, attempts to educate patients are successful. In one study of 371 patients, age greater than 60 years of age, 41% wanted cardiopulmonary resuscitation. After learning the probability of survival, only 22% wanted cardiopulmonary resuscitation. ¹⁸

Completing MOLST Using the 8-Step MOLST Protocol

The MOLST must be completed by a health care professional, based on patient preferences and must be signed by a New York State licensed physician to be valid. Verbal orders are acceptable with follow-up signature by a physician, in accordance with facility or community policy. The original form should remain in the patient's possession as the readily pink color makes it easier to locate in an emergency. Photocopies and faxes of signed MOLST forms are legal and valid. Completion of the entire form is strongly recommended; any section not completed implies full treatment. HIPAA permits disclosure of MOLST to other health care professionals as necessary.

Issues surrounding medical decision-making for patients increasingly challenge physicians. Many studies have shown that most patients either do not have advance directives or, for those patients with advance directives, they do not adequately provide health care professionals with explicit instructions for making critical decisions. ¹⁹ As a result, health care professionals may withhold or initiate treatments that are either not medically indicated or desired by the patient. ²⁰ Further, health care decisions are often made in the face of significant functional health illiteracy with respect to the benefits and burdens, particularly of life-sustaining treatment.

Appendix B on page 51 illustrates the 8-Step Protocol that outlines the suggested process for completion of the MOLST. Informed medical decision-making is assisted by framing the following questions:

• Will treatment make a difference?

- Do burdens of treatment outweigh benefits?
- Is there hope of recovery? If so, what will life be like afterward?
- What does the patient value? What is the goal of care?

Documentation of the patient's and surrogate's preferences will improve the poor concordance often seen between the patient's preferences and the treatments their physicians and their spouses thought they wanted. Discussion of preferences for goals of care, treatment options and setting of care should occur with the patient/family unit as designated by the patient.

Cultural factors strongly influence patients' views about serious illness and may impact the advance care planning process. Appreciating and respecting cultural values and beliefs is essential. It is equally important to recognize that variation exists within a culture. The best method for understanding cultural factors that may impact the patient is simply to ask the patient.

Page 1 of the MOLST provides resuscitation instructions for the patient/resident in cardiopulmonary arrest with no pulse and/or no respirations. By agreeing to CPR, the patient agrees to the entire battery of treatments, including intubation and mechanical ventilation, typically required if the patient/resident survives. To issue a DNR order, Section A, a subsection of B and Section C must be completed. Section A provides resuscitation instructions, a subsection of B provides consent and Section C provides for the physician signature. Consent can be provided by the patient, resident, a duly appointed Health Care Agent or a surrogate decision-maker, in accordance with NYS Public Health law (PHL § 2977). For patients who lack capacity, and/or for therapeutic or medical futility exceptions, and/or for residents of OMH, OMRDD or correctional facilities, relevant sections of the Supplemental Documentation Form for Adults must also be completed. For Minor patients, the Supplemental Documentation Form for Minors must also be completed.

As per Public Health Law § 2967(4)(b), a parent may give a verbal consent in the presence of two witnesses, one of whom must be an M.D. affiliated with the hospital in which the patient is being treated. The decision must be noted in the patient's medical chart.

Page 2 provides for medical orders for other lifesustaining treatment and future hospitalizations if the patient/resident has a pulse and/or is breathing. Additional treatment guidelines are provided, including a recognition that comfort measures are always provided, regardless of the level of intervention chosen. Other choices include intubation and mechanical ventilation instructions in the event of progressive or impending pulmonary failure without cardiopulmonary arrest, future hospitalizations and transfer instructions, use of artificially administered fluids and nutrition, antibiotics, and other individualized instructions (e.g., dialysis, implantable defibrillators, etc.). The physician may complete the MOLST form with the patient who has capacity or with a Health Care Agent. If a Health Care Agent makes a decision regarding artificial hydration and nutrition, the decision must be based on reasonable knowledge of the patient/resident wishes. For the incapacitated patient/ resident without a Health Care Agent, the MOLST can be completed with clear and convincing evidence, established in *In re Westchester County Medical Center*, on behalf of Mary O'Connor. "The ideal situation is one in which the patient's wishes were expressed in some form of a writing, perhaps a 'living will,' while he or she was still competent. The existence of the writing suggests the seriousness of purpose and ensures that the court is not being asked to make a life-or-death decision based upon casual remarks."21 The decision went on to state, "Of course, a requirement of a written expression in every case would be unrealistic. Further, it would unfairly penalize those who lack the skill to place their feelings in writing. For that reason, we must always remain open to applications such as this, which are based upon the repeated oral expressions of the patient." Patients with mental retardation and developmental disabilities with capacity can complete the MOLST form. The physician should consult legal counsel for patients with mental retardation and developmental disabilities without capacity, and follow in accordance with Surrogate's Court Procedure Act 1750B.

The physician should review and renew MOLST periodically, if the individual's preferences change, if the individual's health status changes, and if the patient is transferred to another care setting. The physician must review and renew DNR order at least every 7 days in the hospital, at least every 60 days in the nursing home/SNF, and at least every 90 days in the nonhospital/community setting.

Establishing Plans of Care for Patients Who Lack Decision-Making Capacity

The incidence of cognitive impairment increases with age. Assessing the patient's ability to make decisions is recommended. Capacity is the ability to take in information, understand its meaning and make an informed decision using the information. Intact capacity permits functional independence. Capacity requires a cluster of mental skills people use in everyday life and includes memory, logic, the ability to calculate and "flexibility" to turn attention from one task to another. Medical determination of capacity is often difficult to determine. There is no standard "tool." Capacity assessment is a complex process and is not simply determined by the Mini-Mental Status Exam (MMSE). Capacity assessment should involve a detailed history from the patient, collateral his-

tory from family, focused physical examination, including cognitive, function and mood screens and appropriate testing to exclude reversible conditions. Capacity requirements vary by task. For example, the capacity to choose a trusted individual as an appropriate Health Care Agent differs from the capacity to agree to a medical procedure or treatment.

From a legal perspective, capacity depends on ability to understand the act or transaction, understand the consequences of taking or not taking action, understand the consequences of making or not making the transaction, understand and weigh choices, make a decision and commit to the decision.

Advance care planning for patients lacking decision-making capacity requires special consideration to ensure maximal patient participation with appropriate surrogate involvement.²² Using effective communication skills focused on patient values and goals of care helps surrogate decision makers recognize that goals guide care and the choice of interventions. A mutual appreciation of the patient's condition and prognosis must be reached by physician and family. A choice between life prolongation and quality of life should be offered instead of the choice between treatment and no treatment. The full range of end-of-life decisions from do not resuscitate orders to exclusive palliative care should be addressed.²³ Conversation should be focused to provide evidence of previous repeated oral expression of wishes instead of applying a literal interpretation of an isolated, out-of-context, patient statement made earlier in life. When appropriate, the principle of substituted judgment should be applied, in which the surrogate attempts to establish with as much accuracy as possible what decision the patient would have made if that patient were competent to do so. This standard seeks to preserve the patient's right of self-determination by placing the patient's own preferences at the center of deliberation, while recognizing that it is the exception rather than the rule that the patient will have articulated his or her preferences in advance.

MOLST Pilot Program Legislation

Approved by the New York State Department of Health (NYSDOH) for institutional use, MOLST is spreading to hospitals, long-term care facilities, hospice agencies and home care agencies throughout the state. Although MOLST can now be used *in facilities*, the ultimate goal is to also use MOLST in the community and to improve EMS personnel's ability to treat according to patient wishes.

Governor Pataki signed the MOLST bill (A.8892, S.5785) establishing a pilot of the MOLST program in Monroe and Onondaga Counties on October 11, 2005. This bill allows for the use of the MOLST form *in lieu of* the New York State Nonhospital Do Not Resuscitate

(DNR) form. Do Not Intubate (DNI) is not covered in Nonhospital DNR Law (PHL § 2977). A Chapter Amendment (A.9479, S.6365), signed by Governor Pataki on July 26, 2006, permits EMS to honor Do Not Intubate (DNI) instructions prior to full cardiopulmonary arrest in Monroe and Onondaga Counties during the MOLST Pilot and provides a carve out for persons with mental retardation and developmental disabilities without capacity.

The Monroe and Onondaga Counties MOLST Community Implementation Team was formed to help introduce and oversee the pilot. Team members include representatives from hospitals, long-term care facilities, hospice and home care agencies, EMS personnel, NYSDOH Western Region—Rochester and Syracuse offices, local medical societies, local bar associations and the respective county health departments. The Team facilitates implementation of the pilot and aims to ensure adequate regional training and appropriate utilization of the MOLST form and program. Appropriate utilization will be audited through collecting and reviewing quality EMS and facility-based data. Standardized quality metrics are under development and will be tracked. To assist facility implementation throughout the state, sample Policies and Procedures, Facility Implementation and Education Workplans from the pilot counties are available for replication. The ultimate goal is the creation of a system that ensures that the form and program are appropriately used as the project moves beyond the pilot phase.

Periodic e-mail updates on the MOLST Pilot are sent. Contact patricia.bomba@lifethc.com.

Community Resources

Final products will be produced as a result of the MOLST Pilot Project. Several are currently available, including:

- MOLST 8-Step Protocol, a framework for discussion using the MOLST.
- MOLST Guidebook, a nuts and bolts summary of MOLST.
- MOLST Patient & Family Trifold Brochure, in English and Spanish.
- MOLST Patient & Family Web Flyer, in English and Spanish.
- MOLST FAQs.
- MOLST Train-the-Trainers Manual for Facilities.
- Sample Hospital and Long Term Care Facility Policies & Procedures.
- Sample Hospital and Long Term Care Facility Implementation and Education Workplans.

- MOLST Training Manual, a Train-the-Trainers manual created to ensure consistency of training in the MOLST Pilot counties.
- Advance Care Planning Booklet outlines key elements of the process including the choice of the surrogate decision-maker and the discussion of values, beliefs and preferences.
- Community Conversations on Compassionate Care, a community workshop on advance care planning.
- EMS educational "tools" including a standardized EMS training curriculum and provider protocols. Training will include First Responders (Fire and Police), EMS Personnel and Medical Control (designated Emergency Department Physicians who back up EMS personnel).

For further information about MOLST, see www. compassionandsupport.org.

Next Steps

The MOLST Pilot affords the opportunity to initiate ongoing monitoring of quality, a critical component of the MOLST Program. Evaluation of the effectiveness of the MOLST Pilot Project will build the foundation for statewide expansion of the community-wide implementation of the MOLST form and program. Quality measures will be established for ongoing monitoring of the MOLST Program, including accuracy of completion, appropriate utilization and patient/family and professional satisfaction.

The National Quality Forum Framework and Preferred Practices for Quality Hospice and Palliative Care²⁴ outlines five preferred practices for advance care planning:

- Document the designated surrogate/decision maker in accordance with state law for every patient in primary, acute, and long-term care and in palliative care and hospice care.
- Document the patient/surrogate preferences for goals of care, treatment options, and setting of care at first assessment and at frequent intervals as conditions change.
- Convert the patient treatment goals into medical orders and ensure that the information is transferable and applicable across care settings, including long-term care, emergency medical services, and hospital, such as, the Physician Orders for Life-Sustaining Treatment (POLST) Program.
- Make advance directives and surrogacy designations available across care settings, while protecting patient privacy and adherence to HIPAA regulations, e.g., by Internet-based registries or electronic personal health records.

 Develop health care and community collaborations to promote advance care planning and completion of advance directives for all individuals, e.g., Respecting Choices, Community Conversations on Compassionate Care.

The legal community and health care community have an opportunity and professional obligation to collaborate and make these preferred practices a reality in New York State.

Endnotes

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Dr. Patricia Bomba, Vice President and Medical Director, Geriatrics, Excellus BlueCross, Rochester, New York chairs the MOLST Community Implementation Team and has worked with the New York State Department of Health on the MOLST revision and on the MOLST Pilot legislation. She serves as a member of the Review Committee of the National Quality Forum's "Framework and Preferred Practices for Quality Palliative and Hospice Care," the New York State representative on the National POLST Paradigm Task Force, and a New York State delegate to the 2005 White House Conference on Aging.

APPENDIX A

SEND FORM WITH PATIENT/RESIDENT WHENEVER TRANSFERRED OR DISCHARGED MOLST Medical Orders for Life-Sustaining Treatment Do-Not-Resuscitate (DNR) and other Life-Sustaining Treatments (LST) This is a Physician's Order Sheet based on this patient/resident's current medical condition and wishes. It summarizes any Advance Directive. If Section A is not completed, there are no restrictions for this section. When the need occurs, first follow these orders, then contact physician. Any section not completed implies full treatment for that section. This form should be reviewed and renewed periodically, as required by New York State and Federal law or regulations, and/or if: > The patient/resident is transferred from one care setting or care level to another, or There is a substantial change in patient/resident health status (improvement or deterioration), or The patient/resident treatment preferences change Section RESUSCITATION INSTRUCTIONS (ONLY for Patients in Cardiopulmonary Arrest): (If patient/resident has no pulse and/or no respirations) Do Not Resuscitate (DNR)* [DNR - No cardiopulmonary resuscitation, endotracheal intubation or mechanical ventilation] Full Cardio-Pulmonary Resuscitation (CPR) - No Limitations Check One Box Only * For incapacitated adults; and/or for therapeutic or medical futility exceptions; and/or for residents of OMH, OMRDD or correctional facilities, also complete relevant sections of Supplemental DNR Documentation Form for Adults. For minor patients, also complete Supplemental DNR Documentation Form for Minors. For patients in the community, also complete NYS DOH Nonhospital DNR Form, unless located in Monroe or Onondaga Counties Section DNR (CPR) CONSENT OF PATIENT/RESIDENT WITH DECISION-MAKING CAPACITY: Section A reflects my treatment preferences. B Patient/ Patient/Resident Signature ☐ Check if verbal consent Print Patient/Resident Name Resident/ Health Care Witness of Patient/Resident Signature or Verbal Consent Print Witness Name Date Agent or Surrogate DNR (CPR) CONSENT OF HEALTH CARE AGENT (HCA) OR SURROGATE DECISION-Decision-Maker MAKER FOR PATIENT / RESIDENT WITHOUT DECISION-MAKING CAPACITY: This document Consent for reflects what is known about the patient/resident's treatment preferences. For Patient/Resident without decision-making capacity, Section A. or when medical futility or therapeutic exception is used, Supplemental MOLST Documentation Form MUST be completed and should always accompany this MOLST Form. If patient/resident has a legal and valid DNR previously completed while patient/resident had capacity, attach to MOLST. | Prior form attached | Supplemental Documentation Form completed Complete one of the Print Name Date subsections of Section B Relationship to Patient/Resident: Witness Signature Print Witness Name Date (Must witness HCA/surrogate signature or verbal/telephone consen Section Physician Signature for Sections A and B: Physician Signature Print Physician Name Date Physician (Must Witness Patient/Resident Signature or Verbal Consent) Signature Physician License #: Physician Phone/Pager #: for Section A and B It is the responsibility of the physician to determine, within the appropriate period, (see below) whether this order continues to be appropriate, and to indicate this by a note in the person's medical chart. The issuance of a new form is NOT required, and under the law this order should be considered valid unless it is known that it has been revoked. This order remains valid and must be followed, even if it has not been reviewed within the appropriate time period. The physician must review these orders as follows: Hospital: at least every 7 Days; Nursing Home/Skilled Nursing Facility: at least every 60 Days; Nonhospital/Community Setting: at least every 90 Days Section ADVANCE DIRECTIVES: Patient/Resident has completed an additional document that provides guidance for treatment measures if he/she loses medical decision-making capacity: ☐ Health Care Proxy Living Will

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Section

E

HIPAA Permits Disclosure of MOLST to Other Health Care Professionals as necessary

ORDERS FOR OTHER LIFE-SUSTAINING TREATMENT AND FUTURE

HOSPITALIZATION: (If patient/resident has pulse and/or is breathing)

This Section is "optional" depending on clinical circumstances and setting. Complete only those sub-sections that are relevant. Blank subsections can be completed at a later date. If patient has decision-making capacity, patient should be consulted prior to treatment or withholding thereof. After confirming consent of appropriate decision-maker, physician must sign and date each subsection at the time of completion.

	maker, physician must sign and date each subsection at the time of completion.					
Physician may complete form for patient with capacity or with Health Care Agent. Include Section E consent.	ADDITIONAL TREATMENT GUIDELINES: (Comfort measures are always provided.) □ Comfort Measures Only − The patient is treated with dignity and respect. Reasonable measures are made to offer food and fluids by mouth. Medication, positioning, wound care, and other measures are used to relieve pain and suffering. Oxygen, suction and manual treatment of airway obstruction are used as needed for comfort. Do Not Transfer to hospital for life-sustaining treatment. Transfer if comfort care needs cannot be met in current location.					
	□ Limited Medical Interventions - Oral or intravenous medications, cardiac monitoring, and other indicated treatments are provided except as specified in Sections A or E. Guidance about acceptable/unacceptable interventions relevant to this patient/resident may be written under "Other Instructions" below. Transfer to the hospital as indicated.					
	 No Limitations on Medical Interventions - All indicated treatments are provided except as specified in Sections A. <u>Transfer</u> to the hospital is indicated, including intensive care. 	MD Signature:	Date:			
Physician may complete form for incapacitated patients without Health Care Agent only with clear and convincing evidence. Include Section E consent.	ADDITIONAL INTUBATION AND MECHANICAL VENTILAT resident is DNR, and has progressive or impending pulmonary failure with Do Not Intubate (DNI) A trial period of intubation and ventilation Intubation and long-term mechanical ventilation, if needed					
	FUTURE HOSPITALIZATION / TRANSFER: (For long-term care residents and home patients) No hospitalization unless pain or severe symptoms cannot be otherwise controlled.					
	☐ Hospitalization with restrictions outlined in Sections A and E.	MD Signature:	Dute:			
	ARTIFICIALLY ADMINISTERED FLUIDS AND NUTRITION: (If Health Care Agent makes decision, it must be based on knowledge of patient/resident's wishes.)					
Physician should consult legal counsel for MR/DD patients without capacity. See Surrogate's Court Procedure Act §1750-B.	 □ No feeding tube (offer food/fluids as tolerated) □ No IV Fluids (offer food/fluids as tolerated) □ A trial of IV fluids 					
	☐ Long-term feeding tube, if needed	MD Signature:	Date:			
	ANTIBIOTICS: No antibiotics (except for comfort) Antibiotics	MD Signature:	Date:			
	OTHER INSTRUCTIONS: (May include additional guidelines for starting or stopping treatments in sections above or other directions not addressed elsewhere.)					
		MD Signature:	Dute:			
Section E Consent	CONSENT FOR SECTION F OF PEDSON NAMED IN SECTION R. Significant thought has					
	Signature Check if verbal consent Print Name	Date				

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SEND FORM WITH PATIENT/RESIDENT WHENEVER TRANSFERRED OR DISCHARGED				
RENEW / REVIEW INSTRUCTIONS	Last Name of Patient/Resident			
MOLST (DNR and Life-Sustaining Treatment)				
This form should be reviewed and renewed periodically, as required by New York State and Federal law or regulations, and/or if:	First Name/Middle Initial of Patient/Resident			
The patient/resident is transferred from one care setting or care level to another, or				
There is a substantial change in patient/resident health status	Patient/Resident Date of Birth			
(improvement or deterioration), or				
The patient/resident treatment preferences change				

How to Complete the MOLST Form

>MOLST must be completed by a health care professional, based on patient preference and medical indications.

>MOLST must be signed by a NYS licensed physician to be valid. Verbal orders are acceptable with follow-up signature by a physician in accordance with facility/community policy.

>If patient/resident has a legal and valid DNR previously completed while patient/resident had capacity, attach to MOLST.
>Use of original form is strongly encouraged. Photocopies and FAXes of signed MOLST are legal and valid.

How to Review MOLST Form:

Step 1: Review Sections A through E Step 2: Complete Section F below:

2a. If no changes, sign, date and check the "No Change" box.

2b. For additions to Section E "optional" directives, complete the relevant subsections(s) after securing consent from the appropriate decision-maker, sign and date subsection(s) in Section E. Then sign, date and check "Changes-Additions only" in box below.

2c.For <u>substantive changes</u>, (i.e. reversal of prior directive), write "VOID" in large letters on pages 1 and 2, and complete a new form. Check box marked "FORM VOIDED, new form completed". (RETAIN voided MOLST form in chart or medical record, or as required by law.)

2d.If this form is voided and no new form is completed, full treatment and resuscitation will be provided. Write "VOID" in large letters on pages 1 and 2 and check box marked "FORM VOIDED, no new form." (RETAIN voided MOLST form in chart or medical record, or as required by law.)

	Review of this MOLST Form				
Date	Reviewer's Name and Signature	Location of Review	Outcome of Review		
,			☐ No Change ☐ Changes — Additions only ☐ FORM VOIDED, new form completed ☐ FORM VOIDED, no new form		
			 □ No Change □ Changes – Additions only □ FORM VOIDED, new form completed □ FORM VOIDED, no new form 		
			☐ No Change ☐ Changes — Additions only ☐ FORM VOIDED, new form completed ☐ FORM VOIDED, no new form		
			☐ No Change ☐ Changes — Additions only ☐ FORM VOIDED, new form completed ☐ FORM VOIDED, no new form		
			□ No Change □ Changes – Additions only □ FORM VOIDED, new form completed □ FORM VOIDED, no new form		

Pages 3 & 4 contain directions and renewals only.

Continue Section F on Page 4

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SEND FORM WITH PATIENT/RESIDENT WHENEVER TRANSFERRED OR DISCHARGED Review of this MOLST Form (Con't from Page 3) Section Location of Review Outcome of Review Date Reviewer \mathbf{F} □ No Change ☐ Changes – Additions only (Review ☐ FORM VOIDED, new form completed ☐ FORM VOIDED, no new form of this Form) □ No Change. □ Changes – Additions only □ FORM VOIDED, new form completed ☐ FORM VOIDED, no new form □ No Change □ Changes – Additions only □ FORM VOIDED, new form completed □ FORM VOIDED, no new form □ No Change ☐ Changes - Additions only D FORM VOIDED, new form completed □ FORM VOIDED, no new form ☐ No Change □ Changes – Additions only □ FORM VOIDED, new form completed □ FORM VOIDED, no new form □ No Change Changes – Additions only □ FORM VOIDED, new form completed □ FORM VOIDED, no new form □ No Change □ Changes – Additions only ☐ FORM VOIDED, new form completed □ FORM VOIDED, no new form □ No Change ☐ Changes – Additions only ☐ FORM VOIDED, new form completed □ FORM VOIDED, no new form □ No Change ☐ Changes – Additions only ☐ FORM VOIDED, new form completed □ FORM VOIDED, no new form □ No Change □ Changes – Additions only ☐ FORM VOIDED, new form completed □ FORM VOIDED, no new form □ No Change □ Changes – Additions only □ FORM VOIDED, new form completed □ FORM VOIDED, no new form □ No Change □ Changes – Additions only □ FORM VOIDED, new form completed □ FORM VOIDED, no new form

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APPENDIX B



Medical Orders for Life-Sustaining Treatment (MOLST)*

8-Step MOLST Protocol

- 1. Prepare for discussion
 - Review what is known about patient and family goals and values
 - Understand the medical facts about the patient's medical condition and prognosis
 - Review what is known about the patient's capacity to consent
 - Retrieve and review completed Advance Care Directives and prior DNR documents
 - Determine who key family members are, and (if the patient does not have capacity), see if there is an identified "Agent" (Spokesperson) or responsible party
 - Find uninterrupted time for the discussion
- 2. Begin with what the patient and family knows
 - Determine what the patient and family know regarding condition and prognosis
 - Determine what is known about the patient's views and values in light of the medical condition
- 3. Provide any new information about the patient's medical condition and values from the medical team's perspective
 - Provide information in small amounts, giving time for response
 - Seek a common understanding; understand areas of agreement and disagreement
 - Make recommendations based on clinical experience in light of patient's condition / values
- 4. Try to reconcile differences in terms of prognosis, goals, hopes and expectations
 - Negotiate and try to reconcile differences; seek common ground; be creative
 - Use conflict resolution when necessary
- 5. Respond empathetically
 - Acknowledge
 - Legitimize
 - Explore (rather than prematurely reassuring)
 - Empathize
 - Reinforce commitment and nonabandonment
- 6. Use MOLST to guide choices and finalize patient/family wishes
 - Review the key elements with the patient and/or family
 - Apply shared medical decision making
 - Manage conflict resolution
- 7. Complete and sign MOLST
 - Get verbal or written consent from the patient or designated decision-maker
 - Get written consent from the treating physician, and witnesses
 - Document conversation
- 8. Review and revise periodically

*MOLST is a medical order form designed to provide a single, community-wide document that would be easily recognizable and enable patient wishes for life-sustaining treatment to be honored. It is a tool created by a workgroup of the Community-Wide End-of-life/Palliative Care Initiative in Rochester, New York. MOLST is adapted from the Oregon Physician Orders for Life-Sustaining Treatments (POLST) and incorporates New York State Law.