

MOLST Order Scenarios 8

This Special Edition of Dateline was published to both highlight and address the importance of honoring end-of-life decisions made by patients. If you are a MLMIC policyholder and have any questions not covered in the following article, please do not hesitate to contact the attorneys at Fager Amsler & Keller, LLP by calling the office nearest you, or by utilizing the MLMIC.com Contact Us feature.

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Medical, Ethical and Legal Obligations to Honor Individual Preferences Near the End of Life

Patricia A. Bomba, MD and Jonathan Karmel, Esq.

I. Introduction

The Patient Self-Determination Act¹ affirms an individual's right to accept or refuse treatment. This right does not end when a person is near the end of life. Specifically, an individual has the right to accept or refuse any or all life-sustaining treatment near the end of life. Decisions to forgo life-sustaining treatment may change in the final year of life as the person's health status, prognosis and personal goals for care transition from focusing on longevity, to functionality, to quality of life. A seriously ill person who might die in the next year, and has the ability to make medical decisions regarding life-sustaining treatment, should discuss goals, values and wishes with a physician, and complete the New York State Department of Health (NYSDOH) Medical Orders for Life-Sustaining Treatment (MOLST) form (DOH-5003).²

Based upon the individual's goals for care, the patient may choose to allow natural

death and forgo an attempt at cardiopulmonary resuscitation (CPR). For example, an individual may request a Do Not Resuscitate (DNR) medical order, while still wishing to have a trial of intubation and mechanical ventilation, and hospitalization. As the health status worsens, the patient may consent to a Do Not Intubate (DNI) medical order in addition to the DNR order. When this individual's condition further deteriorates, having no further hospitalizations may be requested by the patient. At each stage, no matter the decision, this individual has a right to be treated with dignity and respect.

Health care providers will always offer comfort measures (palliative care) despite the medical orders to discontinue certain treatment contained in the MOLST. Comfort measures have the primary goal of relieving pain and other symptoms and reducing suffering. Food and fluids will be offered by mouth.

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Dateline is published under the auspices of MLMIC's Patient Safety & Education Committee, Donald J. Pinals, MD, Chairperson.

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Medications, repositioning, wound care, and other measures such as oxygen, suctioning and manual treatment of airway obstruction will also continue to be used to relieve pain and suffering.

There are several statutes governing the ethical framework for withholding and/or withdrawing life-sustaining treatment, if an individual loses the capacity to make these decisions. The Health Care Proxy Law empowers an adult to appoint a health care agent (HCA) to make treatment decisions based on known wishes or best interests.³ The Family Health Care Decisions Act (FHCDA) enables a patient's family member or close friend (Public Health Law surrogate) in a hospital or nursing home setting to make health care decisions when the patient is not able to do so and there is no HCA.⁴ In addition, the Surrogate's Court Procedure Act (SCPA) section 1750-b permits a SCPA Article 17-A guardian or an actively involved family member to make medical decisions for individuals with developmental disabilities (DD) who lack the ability to make these decisions.⁵

HCAs and Public Health Law (PHL) surrogates may not undo health care decisions the patient already made before losing capacity.⁶ Nor can they disregard the preferences and values of the patient, including the patient's religious and moral beliefs, and substitute their own preferences or values when making new health care decisions after the patient loses capacity.⁷ Health care professionals also have an ethical obligation to honor individual preferences and cannot disregard the values, preferences and prior decisions made by the patient in favor of requests for treatment made by the HCA, PHL surrogates, family or other loved ones.⁸

Both FHCDA and SCPA 1750-b have explicit guidelines and special requirements for making decisions to withhold and/or withdraw life-sustaining

treatment. In all cases, the statutes affirm "person-centered" care and require that treatment decisions be based upon the individual's personal values, beliefs and goals for care and not those of the decision-maker.

II. The Ethical-Legal Framework for Making Medical Decisions

A. Health Care Proxy Law

A HCA may make medical decisions on behalf of a patient (principal), after two physicians concur that the patient lacks medical decision-making capacity. A HCA is generally authorized to make decisions as if the HCA were the principal. Occasionally, the health care proxy document may limit the authority of the HCA. A HCA is required to make decisions according to the principal's wishes, including religious and moral beliefs. If these wishes are not reasonably known and cannot with reasonable diligence be ascertained, the HCA may make decisions according to the principal's best interests, except for a decision to withhold or withdraw artificial nutrition or hydration. A HCA is authorized to make a decision to withhold or withdraw artificial nutrition or hydration only if the HCA has reasonable knowledge of the principal's wishes regarding the administration of artificial nutrition and hydration.⁹ "Clear and convincing evidence" of the principal's wishes is NOT needed for a HCA to make decisions about life-sustaining treatment. However, a HCA cannot override a principal's prior instructions to health care professionals or the principal's advance directive.¹⁰

Before choosing a HCA, there are very important issues for the principal to consider. This person must, or at least should:¹¹

- Meet legal criteria (be a competent adult, at least 18 years old);

- Be willing to speak on behalf of the principal;
- Be willing to act on the principal's wishes;
- Be able to separate the HCA's own feelings from those of the principal;
- Live near the principal or be willing to come to that geographical location if needed;
- Know the principal well;
- Understand what values, goals and morals are important to the principal;
- Be willing to discuss sensitive wishes;
- Be willing to listen to wishes expressed by the principal;
- Be willing and able to work with those providing care to the principal to carry out those wishes;
- Intend to be reasonably available in the future;
- Be able to handle potential conflicts between the family and close friends of the principal;
- Be willing and able to handle the responsibility of carrying out end-of-life wishes; and
- If chosen as an alternate, be willing and able to act if the primary HCA is unwilling or unable to act.

B. Family Health Care Decisions Act

Under FHCDA, a surrogate is selected from the surrogate list when there is no HCA to make all medical decisions in a hospital, nursing home or hospice after the attending physician and another health or social services practitioner at the facility have concurred that the patient lacks capacity. For decisions to withhold or withdraw life-sustaining treatment, there are specific clinical criteria which must be satisfied. Additionally, the facility's ethics review committee must agree with the decision in certain situations.¹²

The FHCDA surrogate is also required to make treatment decisions

“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 be ascertained, “in accordance with the patient’s best interests.”¹³

The FHCDA surrogate must be fully informed about the patient’s medical condition and the risks, benefits, burdens and alternatives of possible life-sustaining treatment. The FHCDA surrogate must then consent to withholding or withdrawing life-sustaining treatment, for which medical orders are written. The surrogate’s assessment must be based upon the 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 that a reasonable person in the patient’s circumstances would wish to consider.

C. Surrogate’s Court Procedure Act § 1750-b

SCPA1750-b allows an Article 17-A Guardian or actively involved family members to make medical decisions, including end-of-life decisions related to the withholding and/or withdrawing life-sustaining treatment for individuals with developmental disabilities (DD) who lack the ability to make these decisions. A person with DD who has capacity can make end-of-life decisions. A person with DD who has capacity to choose a HCA can complete a health care proxy and choose a HCA. If the person with DD subsequently loses capacity to make medical decisions, the



HCA then can make decisions in accordance with Health Care Proxy Law. If the person with DD lacks the capacity to make decisions and does not have a HCA, the provisions of SCPA 1750-b apply. In that case, the guardian shall base all advocacy and health care decision-making solely and exclusively on the best interests of the person with DD and, when reasonably known or ascertainable with reasonable diligence, on the person’s wishes, including moral and religious beliefs.¹⁴ Clear and convincing evidence of the patient’s wishes is also not needed in order for a surrogate to consent to MOLST decisions in accordance with FHCDA and SCPA 1750-b.

D. Medical Orders for Life-Sustaining Treatment

Preferences for treatment and decisions about the care of seriously ill persons near the end of life are acutely needed

in an emergency. More often than not, a seriously ill individual lacks the capacity to make these decisions when chronic medical conditions acutely decompensate. MOLST orders provide health care professionals with clear direction for the life-sustaining treatment the individual wishes to receive, as well as those to be avoided, based upon *current*, not future, health status and prognosis.

MOLST is a clinical process that emphasizes the discussion of the patient’s goals for care and shared medical decision-making between health care professionals and patients who are seriously ill or frail, for whom the physician would not be surprised if they might die within the next year. The completion of the MOLST form results in a standardized set of documented medical orders that reflect a patient’s preferences for life-

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sustaining treatment. MOLST, however, is *not* an advance directive.

NYSDOH approved MOLST for use in all health care facilities throughout New York State in October 2005. A Dear Administrator Letter (DAL) was sent to hospitals, nursing homes and EMS in January 2006. Upon completion of a successful community MOLST Pilot Project in Monroe and Onondaga Counties from 2005-2008, legislation enacting MOLST was passed and then signed by then Governor David Paterson. This law also changed the scope of practice for EMS responders across New York State to permit MOLST orders for DNR to be honored in non-hospital settings in addition to non-hospital DNR orders and non-hospital DNI orders only on the MOLST form.

In 2010, MOLST became a NYSDOH form. This is the **ONLY** form approved by NYSDOH for both DNR and DNI orders in the community. All

health care professionals, including EMS, must follow the MOLST orders in all clinical settings, including the community.

On January 21, 2011, the Office for People with Developmental Disabilities (OPWDD) approved use of the DOH-5003 MOLST form for individuals in the OPWDD system in all clinical settings, including the community. However, the individual's physician must follow certain legal requirements before a MOLST can be signed for a DD person. Further, the OPWDD MOLST Legal Requirements Checklist must be attached to the MOLST form.

III. Authority to Make MOLST Decisions

When a patient has properly consented to MOLST orders via a shared, informed medical decision-making process and has made decisions regarding life-sustaining treatment, the MOLST form will document the patient's wishes,

given the patient's current health status and prognosis.

A HCA **CANNOT** overrule the clear wishes of the principal as expressed in the MOLST, unless the agent has a good faith basis for believing that the principal's wishes have changed or do not apply to the present circumstances (e.g., the principal's condition has changed, and he or she would have made a different decision, had he or she known about the change). Similar logic is applied when a surrogate makes MOLST decisions in accordance with FHCDA and SCPA1750-b.¹⁵

A. An Example of What Should Happen with MOLST

A nursing home resident indicated that he wished to meet a life goal—e.g., attend a grandson's wedding. Because of that, he requested to receive full treatment, including CPR, on his MOLST. His daughter was his HCA. She was aware of his goals for care based upon his current health status. He then had a catastrophic stroke, which precluded the possibility he could attend his grandson's wedding. This major change in his health status triggered a review of his MOLST orders. Since his HCA stood in the principal's shoes, she had to establish new goals for his care and treatment based upon his prior preference that he did not wish to live hooked up to machines like his late brother. Therefore, a palliative approach was discussed with the HCA with the focus on the quality and not the longevity of his life. The HCA could then request the change in the MOLST orders in accordance with the principal's wishes based upon the change in circumstances and the determination of new goals for care.

If, however, this same resident had previously consented to DNR/DNAR/Accept Natural Death on page 1 and Limited Medical Interventions on page 2 of the MOLST, the HCA could not "undo" the DNR order, because the MOLST

had provided a clear statement of the resident's wishes and represented *clear and convincing evidence*. There was in that instance no reason to believe that the resident's wishes would have changed or would not have been applicable in the event of a catastrophic stroke. The MOLST DNR order provides more than just "reasonable knowledge" of the principal's wishes; it provides clear documentation of those wishes.

B. One of the Most Frequently Asked MOLST Questions

One of the most frequently asked questions with respect to MOLST is whether a HCA or a PHL surrogate can demand life-sustaining treatment and hospitalization for a nursing home resident, when the resident loses capacity and the resident's health status worsens. If that request conflicts with the resident's prior decisions, made when the resident had capacity and the medical orders were issued by the attending physician on the MOLST, the answer is NO. Yet this situation continues to occur.

C. An Example of What Should Not Happen with MOLST

A 77-year-old female with multiple medical conditions, including agoraphobia, was admitted to a nursing facility approximately six years ago, when she was no longer able to manage her activities of daily living. Her family rarely, if ever, visited or communicated with her. Her grandson served as her HCA. At the time of her admission, she had the capacity to make medical decisions.

About four years ago, she began to refuse to leave her bed with very rare exceptions. As a result, she developed severe pressure sores due to her refusal of bathing, turning, and positioning. Serial psychiatric consultations were obtained. These confirmed that the patient still had the capacity to understand the risks and benefits associated with her refusal of care.

Approximately two-and-a-half years later, her attending physician and the psychiatrist both agreed she continued to have the capacity to make decisions regarding life-sustaining treatment. A MOLST form was completed. Her goals for care were to focus on the quality of her life. She specifically wished to avoid aggressive interventions, and wanted to die a natural death in the nursing home, being cared for by the staff who had served as her surrogate family. Her MOLST reflected DNR, DNI, no feed-

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ing tubes, no hospitalization and Comfort Measures Only. Her goals and preferences for care and treatment remained unchanged with the passage of time, when the MOLST orders were reviewed and renewed in accordance with the nursing home's policies and procedures.

The resident became acutely ill with symptoms of sepsis, a diffuse infection likely due to the pressure sores. The nurse practitioner (NP) contacted her HCA to review her acute deterioration in health status and to review the treatment plan, which was consistent with his grandmother's previously made decisions and goals. Her grandson stated he understood his grandmother's wishes and was

supportive of the palliative care plan of care. The resident was treated with antibiotics and comfort measures.

However, over the next three days, her oral intake diminished. She ultimately stopped eating and drinking and appeared to be imminently dying. The NP again called the grandson to update him of her continuing decline. He subsequently arrived at the facility and insisted that the resident be transferred to the hospital for acute care, violating his grandmother's known wishes and already executed medical orders. The NP spoke with him to try to help him deal with the reality of the situation. She refused to call 911, because she and all the facility staff knew what the resident wanted and didn't want. However, the grandson called 911. When EMS arrived, the grandson allegedly became quite agitated. He insisted that his grandmother be transported to the hospital. After reviewing the MOLST, the EMS staff called Medical Control for guidance. Because of the grandson's agitation, the resident was transferred to the Emergency Department. She was then admitted to the facility's intensive care unit, where she had a stormy and painful medical course and ultimately died. An analysis of this case revealed the following due to the failure to follow the resident's MOLST orders:

- The resident's legal rights and decisions as evidenced by her MOLST orders were violated. She was transferred against her will and without her consent, and her right to refuse treatment was violated.
- From a medical perspective, the medical staff erroneously failed to follow her documented wishes, in part due to the agitation of the HCA.
- The nursing home staff felt immense moral distress. They felt they had failed their ethical obligations to the resident.

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- From a regulatory perspective, there were also violations. CMS Clinical Standards and Quality for Advance Care Planning Survey Deficiency F tag 155 states clearly that the failure to follow MOLST orders by allowing hospitalization results in “Immediate Jeopardy.”¹⁶

Unfortunately, the provisions of the Public Health Law are not always sufficient to ensure that patient rights will be respected.

IV. Why There Are Failures in Following MOLST Orders

- Clinicians, patients, families and medical decision makers are unaware of their moral, ethical and legal obligations to follow MOLST orders and the implications of their failure to follow MOLST orders.
- Unfortunately, advance care planning is not recognized by everyone as a dynamic communication process. Too often, the emphasis is placed on the completion of the forms rather than the communication process. Many clinicians have difficulty with having the discussion and have inadequate training in conflict resolution.
- Sometimes when the attention of the physician is primarily directed on the conversation, appropriate legal documents and/or medical orders may not be completed or may be completed incorrectly.
- One of the most serious problems is that family members tend to avoid having conversations centered on the personal values, beliefs and goals for care. Thus, they do not really understand what matters most to the individual seeking MOLST orders.
- Sometimes the patient has chosen the wrong HCA.
- There is also a lack of understanding by both health care professionals and family of the difference between a

traditional advance directive (health care proxy and/or living will) and medical orders (MOLST).

- The assessment of capacity determinations and documentation of capacity as well as the patient’s personal values, beliefs and goals for care and the statutory requirements may either be absent or inadequate. Therefore, all of these problems may affect whether a MOLST is or can be honored.
- Unfortunately, the health care system is fragmented. Therefore, key information may not be consistently accessible when there are transitions in patient care. Further, health care professionals are not always able to easily access advance directives and/or MOLST orders in the patient’s medical record.

V. Recommendations

A. Clinician Training Should Be Strengthened

In 2014, the Institute of Medicine (IOM) released “Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life,” a comprehensive review of end-of-life care in the U.S.¹⁷ The IOM report concluded that the U.S. health care system was poorly designed to meet the needs of patients near the end of life and that major changes to the health care system were needed to meet end-of-life care needs and informed patient preferences in a high-quality, affordable, and sustainable manner. The report proposed a high national priority for a patient-centered, family-oriented approach to care near the end of life.

The Committee recommended the development of quality standards for clinician-patient communication and advance care planning. They also recommended the development of appropriate provider training, certification and licensure to strengthen palliative care knowledge and skills for all clinicians. Because advance care planning and MOLST are key elements of palliative care, they must be integrated into the curricula of all

medical, nursing, social work and chaplaincy schools.

B. Public Education and Engagement in Advance Care Planning Should Be Encouraged

“Most people nearing the end of life are not physically, mentally, or cognitively able to make their own decisions about care. The majority of these patients will receive acute hospital care from physicians who do not know them. Therefore, advance care planning is essential to ensure that patients receive care reflecting their values, goals, and preferences.”¹⁸

However, many people do not understand the need for advance care planning, which is the process of planning for future medical care in the event individuals lose the capacity to make their own medical decisions. Lack of capacity can occur suddenly due to unexpected illness or injury, from which an individual may or may not recover. In either case, when an acutely ill person is near death or actively dying, end of life decisions are needed. Advance care planning helps ensure that the patient’s treatment preferences are documented, regularly updated, and respected.

Early initiation of advance care planning is relevant at all ages. No age group is immune from acute illness or injury, complex chronic conditions or death. Improving communication and advance care planning is critically important for persons of all ages who are facing the end of life, including adults, adolescents and children. Fact-based public education that encourages advance care planning and shared medical decision-making that is well informed should be made available along the life cycle.

New York State has developed and implemented a community approach to advance care planning with two complementary programs that were highlighted in the IOM Report: The programs were Community Conversations on Compassionate Care (CCCC)¹⁹ and MOLST. Positive outcomes were achieved

and lessons were learned from more than a decade's experience.²⁰

C. The Use of eMOLST Should Be Expanded

eMOLST²¹ is a web-based application that allows eMOLST orders and documentation of the conversation to be accessed from anywhere with Internet access. New York's eMOLST system is accessible to all users at all times at www.NYSeMOLSTregistry.com.

eMOLST helps health professionals follow a standard clinical process for the MOLST discussion and guides them through all necessary documentation of the ethical framework and legal requirements. The system includes programming to prevent errors and allows physicians to sign MOLST orders electronically. At the end of the eMOLST process, both a DOH-5003 MOLST form²² and the appropriate MOLST Chart Documentation Form for Adult Patients²³ or Minor Patients²⁴ (aligns with NYSDOH Checklists)²⁵ or the OPWDD MOLST Legal Requirements Checklist for Individuals with Developmental Disabilities²⁶ are created. eMOLST works for all patients: adults, children and persons with developmental disabilities.

New York's MOLST forms can be completed online in eMOLST and are automatically included in the registry.

A copy can be printed for the patient. eMOLST does not require or rely on an EHR system and can be used with paper records. eMOLST is operational statewide and currently operates in all browsers and all devices, including on tablets. eMOLST ensures quality and patient safety, reduces patient harm and helps achieve the triple aim, improving the care experience, health outcome and reducing cost. Use of eMOLST is important, since key policy recommendations in the IOM Report include certain specific relevant actions. These include:

- The encouragement of all states to develop and implement a Physician



Orders for Life-Sustaining Treatment (POLST) paradigm program in accordance with nationally standardized core requirements.

- The requirement to use interoperable electronic health records that incorporate advance care planning to improve the communication of individuals' wishes across time, settings, and providers, documenting (1) the designation of a surrogate/decision maker, (2) patient values and beliefs and goals for care, (3) the presence of an advance directive, and (4) the presence of medical orders for life-sustaining treatment for appropriate populations.

Fortunately, the New York State MOLST is a nationally endorsed POLST Paradigm Program. Further, eMOLST is the only such model in the country and was cited in the IOM Report.²⁷

VI. Conclusion

As the populations of both New York State and the United States of America age, the importance of the implementa-

tion of advance care planning is significant. Encouraging the completion of advance directives such as the Health Care Proxy, discussions by physicians with patients about their values, wishes and goals and implementing the use of eMOLST to facilitate the completion of MOLST forms is crucial. Finally, end-of-life wishes of patients must be honored by all parties and greater efforts must be made to educate both the general population and all health care professionals. ❖

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The scenarios below represent common situations healthcare providers encounter when dealing with MOLST orders.

Scenario 1 – Updating MOLST Orders When the Patient Lacks Capacity

A 66-year-old female residing in a nursing home had advanced vascular dementia, hemiplegia, and dysphagia. She had been receiving tube feedings since she had a stroke. She had recently fractured her hip. After that, her cognitive status worsened and her functional status rapidly deteriorated. She could only minimally communicate verbally and required total assistance with all of her care. She had most recently been hospitalized due to aspiration. Her attending physician estimated her life expectancy was three to six months. She had neither a healthcare agent nor any family or close friends. However, she had given written consent for MOLST orders when she had capacity. She now lacked capacity. Therefore, her prior goal of returning home after recovering from her stroke was no longer realistic. Nor were other decisions made when she originally signed the MOLST form. The nursing home then questioned whether her MOLST orders could now be revised and, if so, how this should be done.

Discussion

Because MOLST orders are not static, they must be reviewed in accordance with the time periods delineated in the Public Health Law. Since the patient was in a nursing home, her MOLST form had to be reviewed in accordance with the home's policies and procedures, but no

less than every 90 days. Because of her deteriorating health status, the person-centered goals for her care clearly needed review and re-evaluation. Although the patient had no family or close friends, there were applicable provisions of the Family Health Care Decisions Act (FHCDA) which could be used to allow these orders to be updated and changed. If two physicians determined that the clinical standards for discontinuing life sustaining treatment were met, this patient's MOLST orders could be changed to reflect the changes in her con-

Family may contest valid MOLST forms or other advance directives containing end-of-life decisions because they disagree with the patient's decisions for moral, religious, or emotional reasons. However, they cannot overturn the patient's decision.

dition. The New York State Department of Health has developed a form entitled "checklist 4" which must be followed in this type of situation.¹ Further, there is a MOLST Chart Documentation form (CDF4) which is available on the CompassionAndSupport.org website.² This form aligns with the Department of Health checklist and thus provides guidelines to ensure compliance with docu-

1. http://www.health.ny.gov/professionals/patients/patient_rights/molst/docs/checklist_4.pdf, accessed on November 13, 2015.
2. http://www.compassionandsupport.org/pdfs/professionals/molst/MOLST_Chart_Documentation_Adult_Checklist_4.120110_.pdf, accessed on November 13, 2015.

mentation requirements for such assessments and decisions. Because the orders were in fact changed, a new MOLST form had to be completed. The ability to make such changes reflected the patient's current deteriorating status and prevented her MOLST orders from being static so that life prolonging treatment would not have to be provided to her.

Scenario 2 – Can MOLST Orders be Contested?

A 40-year-old man with severe end stage multiple sclerosis was admitted to a hospital in acute respiratory failure. He had consented to MOLST orders when he had capacity. Although his MOLST orders clearly stated that he did not want even a trial of intubation, when he was brought to the emergency department by EMS, his MOLST form did not accompany him. Because he did not know about the patient's MOLST orders, the emergency physician intubated him.

The patient's healthcare agent was his 18-year-old daughter. He was divorced. Both she and his parents arrived at the facility after the patient was admitted. The patient's own physician came to see him and showed the patient's MOLST form to his family. He advised them that the patient had refused intubation. However, both the healthcare agent and the patient's parents adamantly refused to allow the patient to be extubated. Further, they questioned the validity of his MOLST orders, despite the fact that the patient had capacity when he gave consent and the MOLST form had been reviewed with him every three months and documented as required by law. Because of this, the family then retained an attorney to contest the validity of the patient's MOLST form. In order to attempt to resolve this dispute without

litigation, the physician consulted with both hospital administrators and legal counsel. He proposed lightening the patient's sedation and then asking him about his wishes in the presence of the family, to which they agreed. When the patient became alert and regained capacity, he confirmed his desire to have the intubation discontinued. The family then decided not to contest his decision, after being advised by their counsel that they had no legal basis to do so. The patient was extubated and died peacefully.

Discussion

Family may contest valid MOLST forms or other advance directives containing end-of-life decisions because they disagree with the patient's decisions for moral, religious, or emotional reasons. However, they cannot overturn the patient's decision. When this occurs, the facility and physicians must act reasonably to both support the patient's right to self-determination in making such decisions and also emotionally support the family to accept them. The law clearly permits physicians to honor MOLST orders consented to by patients who had capacity when the MOLST form was signed.

Neither the patient's parents nor his teenage daughter had ever participated in any discussions with the patient about his end of life wishes. It was not until the physician met with the healthcare agent and family at the hospital that they learned what the patient wanted. The physician informed them that the patient had confirmed his wishes multiple times during review of the MOLST orders. The hospital risk manager and a social worker also met with the family to educate them about MOLST and the law. Despite this, the family would not agree to allow the physician to comply with the patient's wishes, until the patient himself confirmed his wishes to them.

This case identified several impor-

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tant issues. An individual must choose a healthcare agent who knows and is willing to carry out the decisions made in accordance with the person's known wishes. If the patient's wishes are not known, the agent must still act in the best interests of the patient. In this situation, appointing a very young adult daughter as the healthcare agent was not a good choice for many reasons.

This case also highlights the need for a patient to discuss end of life requests with the proposed healthcare agent and other family members and loved ones. By doing so, the individual can determine whether the healthcare agent will be willing and able to honor the patient's wishes, despite the agent's own emotions and desires. Because a patient's family or healthcare agent may not be present during the MOLST discussion, we recommend that the patient and physician have a follow-up conversation with them in person or by telephone. Fortunately, there is now improved reimbursement for trained and qualified providers and physicians to engage in such discussions with family and patients about end-of-life decisions. If such a discussion had occurred before this crisis, the patient might have recognized that neither his adult child nor his parents were appropriate to be his healthcare agent. He might have learned that they disagreed with his preferences and the MOLST orders and would try to contest them. What the family did not comprehend was that when a patient with capacity consents to MOLST orders, these orders are valid and must be honored.

Scenario 3 – *eMOLST*

An 82-year-old male was brought to the emergency department in acute respiratory failure. He had multiple medical conditions including congestive heart failure (CHF), chronic obstructive



pulmonary disease (COPD), and chronic renal insufficiency. He was a smoker and had undergone a lobectomy for lung cancer. Recently, he had been hospitalized multiple times due to acute respiratory exacerbations. While he had capacity, he had consented to MOLST orders. The MOLST form had been reviewed by the patient and his physician as required. He also had appointed a healthcare agent. Unfortunately, when EMS came to his home to transport him to the hospital for this hospitalization, they did not bring his MOLST form, which was taped to his refrigerator. The emergency department physician evaluated him. He planned to intubate him and put him on mechanical ventilation prior to transferring him to a tertiary center. However, this hospital uses eMOLST, which is an electronic version of MOLST. When the physician signed into the eMOLST registry, he located the patient's MOLST form. The patient's goals for care were to be able to function and remain at home. His MOLST orders included both DNR (Do Not Resuscitate) and DNI (Do Not Intubate) orders. Because of this, the physician neither intubated nor transferred the patient. Rather, the patient was admitted to the

hospital, treated conservatively, and discharged home. He died two months later at his home, as he had wished.

Discussion

eMOLST is a secure web-based application that permits enrolled users such as hospitals, nursing homes, hospices, and physician practices to complete the eMOLST form. It has two striking advantages. eMOLST serves as New York State's eMOLST registry. Thus, MOLST forms and documentation forms can be accessed in an emergency as in the above scenario. Therefore, EMS, medical providers, and hospitals can have access to the forms at all sites of care. Further, eMOLST is simple to use and facilitates completion of the form, preventing errors which would otherwise invalidate a MOLST form. In this situation, the use of eMOLST allowed the physician to honor the wishes the patient had expressed on his MOLST form and the patient was able to avoid unnecessary and undesired end of life treatment. Thus, eMOLST achieves the triple aim: better health, better care experience, and reduced cost. ❖

Endnotes

1. Patient Self-Determination Act of 1990, P.L. 101-508, § 4206 (codified in 42 USC § 1395cc(f)).
2. NY Public Health Law (PHL) § 2994-dd(6); 10 NYCRR § 400.21(b) (6); New York State Department of Health (NYSDOH) Medical Orders for Life-Sustaining Treatment (MOLST). https://www.health.ny.gov/professionals/patients/patient_rights/molst/.
3. PHL § 2982(2). Under PHL Article 29-C, the term “health care proxy” refers to the document; the term “health care agent” refers to the person appointed. PHL § 2980(5), § 2980(8).
4. PHL Article 29-CC.
5. SCPA 1750-b(4).
6. PHL §§ 2981(4); 2982(1); 2989(2); 2994-d(3)(a)(ii).
7. PHL §§ 2982(2); 2994-d(4).
8. PHL §§ 2964(2)(c); 2994-f; 2994-ee.
9. NYSDOH MOLST Checklist 2 – adult with health care proxy any setting (5/1/13), available at https://www.health.ny.gov/professionals/patients/patient_rights/molst/docs/checklist_2.pdf.
10. Burke, K., Herb, A. and Swidler, R. Three Stubborn Misconceptions About the Authority of Health Care Agents, NYSBA Health Law J., 10(3):63-70 (Summer/Fall 2005).
11. Choose a Spokesperson (Choose the Right Health Care Agent), https://www.compassionandsupport.org/index.php/for_patients_families/advance_care_planning/choose_a_spokesperson.
12. Deciding About Health Care: A Guide for Patients and Families, <http://www.health.ny.gov/publications/1503.pdf>. NYSDOH MOLST Checklist 3 – adult with FHCDA surrogate (3/2012), available at https://www.health.ny.gov/professionals/patients/patient_rights/molst/docs/checklist_3.pdf.
13. PHL § 2994-d(4)(a).
14. SCPA 1750-b(2).
15. Indeed, a health care provider need not seek the consent of a surrogate under FHCDA when the patient has already made a decision about the proposed health care. PHL § 2994-d(3)(a)(ii).
16. Center for Clinical Standards and Quality/Survey & Certification Group F tag 155 <http://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-13-16.pdf>. Hospital patients and nursing home residents have a right to refuse medical treatment. 10 NYCRR §§ 405.7(b)(10); 415.3(e)(1)(ii).
17. IOM Report Dying in America: Improving Quality, Honoring Individual Preferences Near the End of Life, <http://www.iom.edu/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx>.
18. IOM Report Dying in America: Improving Quality, Honoring Individual Preferences Near the End of Life Key Findings and Recommendations <https://www.iom.edu/-/media/Files/Report%20Files/2014/EOL/Key%20Findings%20and%20Recommendations.pdf>.
19. Community Conversations on Compassionate Care, https://www.compassionandsupport.org/index.php/for_patients_families/advance_care_planning/community_conversations.
20. Bomba, P. and Orem, K. Lessons Learned from New York’s Community Approach to Advance Care Planning and MOLST. Annals of Palliative Medicine, 2015; 4(1):10-21, <http://www.compassionandsupport.org/pdfs/research/Bomba.Orem.LessonsLearnedNY.ACP.MOLST.0115.pdf>.
21. NYS eMOLST Registry, <https://www.NYSeMOLSTRegistry.com>.
22. DOH-5003 MOLST Form, <https://www.health.ny.gov/forms/doh-5003.pdf>.
23. MOLST Chart Documentation Form for Adult Patients, http://www.compassionandsupport.org/index.php/for_professionals/molst/checklists_for_adult_patients.
24. MOLST Chart Documentation Form for Minor Patients, http://www.compassionandsupport.org/index.php/for_professionals/molst/checklist_for_minor_patients.
25. NYSDOH MOLST Legal Requirements Checklists for Adults and Minors, http://www.health.ny.gov/professionals/patients/patient_rights/molst/.
26. OPWDD MOLST Legal Requirements Checklist for Individuals with Developmental Disabilities, http://www.opwdd.ny.gov/opwdd_resources/information_for_clinicians/MOLST.
27. IOM Report Dying in America: Improving Quality, Honoring Individual Preferences Near the End of Life, <http://iom.nationalacademies.org/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx> 3-50, Box 3-3.

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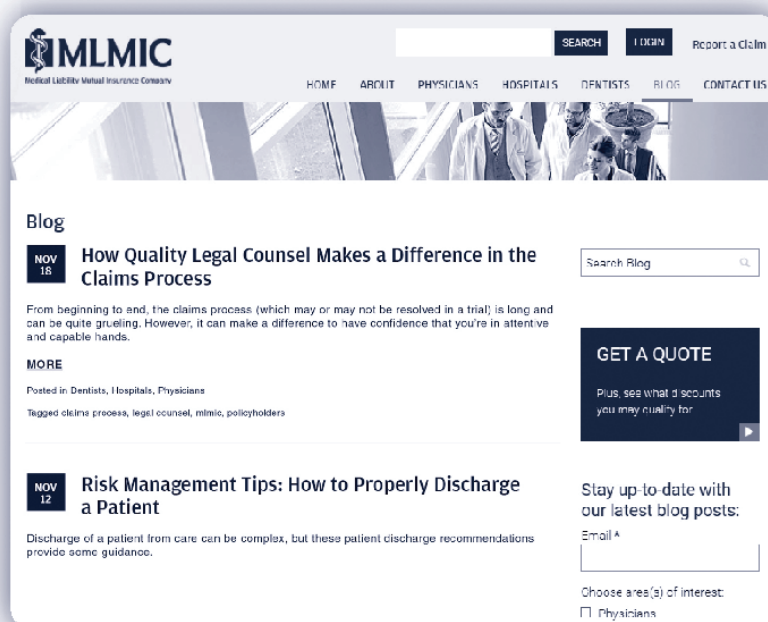


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