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Honoring Patient Preference at the End of Life: The MOLST Process and the Family Health Care Decisions Act

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Introduction

Patient self-determination and informed consent are fundamental elements of medical care in the United States. When a patient loses the capacity to make medical decisions, securing informed consent and carrying out the patient's wishes raise complex legal and ethical issues. These issues are particularly challenging when the patient is near the end of life and decisions must be made about whether or not to provide life-sustaining treatment. Advances in medical care in the last fifty years have enabled us to prolong life where death was once imminent, but often cannot promise an acceptable quality of life. As a result, patients and family members today face difficult choices about how they will live and die.

Since the late 1980s, New York State and the federal government have sought to encourage patients with advanced, life-limiting conditions to make decisions concerning life-sustaining treatment in advance so that, in the event that they lose decision-making capacity, their wishes can be honored. Enacted in 1990, New York's health care proxy law provides a mechanism for competent adults to appoint health care agents to make medical decisions on their behalf in the event that they lose the capacity to make those decisions. The federal Patient Self-Determination Act, enacted in 1991, requires hospitals, nursing homes, hospice programs and home health agencies to inform patients upon admission about their decision-making rights, ask them about advance directives, such as health care proxies and living wills, and document those directives in their medical records.[1]

Despite these efforts, studies have shown that the majority of seriously or terminally ill patients lack advance directives.[2] Moreover, the evidence suggests that the treatment people receive at the end of life is different from the treatment they would have requested, and often the care received is more aggressive than they would have wanted. Opinion polls indicate that a sizeable majority of patients would prefer to die at home.[3] Yet, approximately one in five Americans dies in an intensive care unit, and almost one-third die in a hospital.[4] Another 22 percent die in a nursing home.[5] According to the Dartmouth Atlas on Health Care, Medicare beneficiaries in New York have the highest rate in the U.S. of inpatient days during the last six months of life—15.5 days per deceased patient.[6] Even among Medicare beneficiaries with advanced cancer, the rate of hospital deaths is surprisingly high. About 29 percent die in a hospital, and only about half receive hospice care.[7] The rate of hospital deaths for these patients was the highest in the Manhattan hospital referral region, while hospice use in that region was significantly lower than the national average.[8]

In the absence of advance care planning and an advance directive, when a patient loses decision-making capacity, health care providers and family members often struggle mightily to make treatment decisions consistent with the patient's wishes and values and with New York's laws governing informed consent. Often these difficult decisions are made in the midst of a crisis with little opportunity for reflection. Futile and burdensome treatment may be provided, or life-sustaining treatment may be withheld, without a clear understanding of what the patient would have wanted, causing distress and guilt for family members.

Until June 2010, when an adult patient in New York lacked capacity to make medical decisions and had not appointed a health care agent or executed a living will, family members were legally authorized to consent only to a do not resuscitate (DNR) order. Decisions to withhold other life-sustaining treatment, such as artificially administered nutrition or hydration, could be made only with clear and convincing evidence of the patient's wishes or pursuant to a court order. As a result, patients near death sometimes languished in hospitals receiving futile treatment that family members knew the patient would not want. With the enactment of the Family Health Care Decisions Act (FHCDA),[9] effective June of 2010, family members and close friends can be surrogates with authority to make any treatment decision on behalf of a patient who lacks capacity. While FHCDA facilitates health care decisions for vulnerable patients, it will not succeed in promoting patient autonomy unless prospective surrogates are familiar with their loved one's goals for care, treatment preferences, and values. This can be accomplished through effective advance care planning.

Even when an advance directive is completed, if it does not transition with the patient between health care settings, it may be ineffective in assuring that the patient's care reflects his or her wishes and values. Between 25 and 30 percent of dying patients are cared for in three or more settings in the last months of life.[10] In addition, advance directives may not be implemented properly if they are not discussed with the patient's family members in advance of a crisis. Absent these discussions, an advance directive may be too vague to provide effective guidance to clinicians and family members when the need for a decision arises. In a 2008 report to Congress, the U.S. Department of Health and Human Services concluded that many of the barriers to effective advance care planning could be addressed through adoption of the POLST (Physician Orders for Life-Sustaining Treatment) process:

> Encouraging additional POLST efforts that translate chronic care patient's [sic] care goals into easily identifiable, portable and renewable medical orders that follow the patient across settings would go a long way toward enhancing advance care planning in this country.[11]

POLST, known in New York as "MOLST" (or Medical Orders for Life-Sustaining Treatment), is a national model for advance care planning that supports shared, informed decision making, portability of advance directives across health care settings, and continuity of care.

This article will discuss how the MOLST process works, the law governing decisions to withhold and withdraw life-sustaining treatment in New York State, and the legal basis for the MOLST process. It will describe how the enactment of FHCDA has affected MOLST. Finally, it will describe the MOLST legal checklists developed by the New York State Department of Health (DOH), and the applicable law for patients in facilities licensed by the Office for People With Developmental Disabilities (OPWDD) and the Office of Mental Health (OMH).

The MOLST Process

New York's MOLST process is based on the POLST Paradigm Program initiated in the mid-1990s. Approximately 25 states have active or developing POLST programs. In another seven states, POLST has been adopted at the local or regional level.[12]

With the goal of providing patient-centered care and shared decision making, POLST provides a structured framework for conversations between physicians and their patients (or the patient's authorized decision-maker) concerning prognosis, the benefits and burdens of the life-sustaining treatment and the patient's personal goals for care. The product of the dialogue is concrete, actionable orders recorded on a portable, easily identified form. Studies have shown that POLST is useful in initiating conversations about end-of-life care, in preventing unwanted resuscitations and hospitalizations, and in documenting a range of treatment options.[13]

Ideally, a completed MOLST form is the culmination of a conversation or series of conversations between a competent patient and his or her physician and family members.[14] Although health care agents and FHCDA surrogates may consent to MOLST orders on behalf of patients who lack medical decision-making capacity, the best way to assure patient self-determination is for the patient to make these decisions while he or she has capacity to do so. Family members and/or close friends are typically included in these discussions so that they develop an understanding of the patient's goals for care and values and, in the event that the patient loses capacity, will be able to make decisions consistent with their loved one's wishes and beliefs.

After discussing the patient's prognosis, goals for care, values, options, and any prior advance directives with the patient, his or her family members, and/or close friends, the physician reviews the MOLST form (DOH-5003) with the patient and family and completes and signs it. In some physician practices and facilities, a portion of the conversation may be facilitated by a nurse or social worker; however, a licensed physician must always, at a minimum: (i) confer with the patient and/or the patient's health care agent or surrogate about the patient's diagnosis, prognosis, goals for care, treatment preferences, and consent by the appropriate decision-maker, and (ii) sign the orders derived from that discussion.

The form is bright pink so it can be found and identified easily by emergency medical services personnel responding to a call and by health care facility staff when it is placed in a medical record. The form includes specific orders concerning resuscitation, intubation, future hospitalization, artificially administered hydration and nutrition, administration of antibiotics and general treatment guidelines, such as "comfort measures only," "limited medical interventions," and "no limitations on medical interventions." The form requires the signature of the physician. Either the name or the signature of the person consenting to the orders must be included on the form. In addition, the name(s) of the witness(es) to the consent must be included on the form as well.[15]

The MOLST form is effective in the community and in health care facilities and is intended to accompany the patient as he or she transitions from one setting to another. Under FHCDA, rules governing the implementation of orders to withhold or withdraw life-sustaining treatment upon inter-institutional transfer between hospitals or nursing homes also govern non-hospital orders upon transfer to a hospital or nursing home from the community.[16] Such orders remain effective until an attending physician examines the patient, and either continues the prior orders or determines that they are no longer appropriate or authorized and cancels them.[17] Before canceling them, the attending physician must make reasonable efforts to notify the person who consented to the orders and the hospital staff directly responsible for the patient's care. If the notice cannot be made prior to the cancellation, it must be made as soon as practicable afterwards.[18]

Although this article focuses on decisions to withhold or withdraw life-sustaining treatment, due to the complex laws surrounding such decisions, the MOLST process does not presume an outcome that limits interventions. The form includes a range of options from "attempt CPR" and "no limitations on medical interventions" to "allow natural death" and "comfort measures only." The process is not intended to limit in any way the choices of patients and families, but rather to empower them to make choices consistent with the patient's wishes, values and goals.

The Law Governing Decisions to Withhold or Withdraw Life-Sustaining Treatment in New York State

Decisions to withhold or withdraw life-sustaining treatment may be made in several different ways in New York State. A person with capacity to make medical decisions may consent to a specific medical order prior to losing capacity.[19] Or, under New York common law, health care providers may withhold or withdraw life-sustaining treatment from a patient who is dying and currently lacks the capacity to make his or her own decisions, if doing so is based upon clear and convincing evidence of the patient's wishes.[20]

Under New York's health care proxy law (Public Health Law Article 29-C), health care agents can make decisions to withhold or withdraw life-sustaining treatment even where patients have not left clear and convincing evidence of their wishes. The agent must make decisions in accordance with the principal's wishes, or if the principal's wishes are not reasonably known and cannot with reasonable diligence be ascertained, in accordance with the principal's best interests.[21]

The agent's authority to make decisions concerning the withholding or withdrawing of artificial nutrition and hydration is somewhat limited. If the principal's wishes concerning artificial nutrition and hydration are not reasonably known and cannot with reasonable diligence be ascertained, the agent does not have authority to make decisions regarding these measures.[22] However, it is not necessary to have clear and convincing evidence of a patient's wishes to satisfy the health care proxy law's standard of "reasonably knowing" the patient's wishes. Patients may explicitly state their treatment wishes on their health care proxy, in which case the health care proxy is also functioning as a living will.

When patients lack capacity, have not left clear and convincing evidence of their wishes and do not have a health care proxy, New York law authorizes specified individuals to serve as surrogates to make decisions to withhold or withdraw life-sustaining treatment discussed in more detail below. New York has allowed surrogate health care decision making for DNR orders since Public Health Law (PHL) Article 29-B was enacted in 1987. In 1991, Article 29-B added provisions for non-hospital DNR orders. DOH created the "standard form" to issue a non-hospital order not to resuscitate (DOH-3474), which is still in use today. With the enactment of FHCDA, surrogates may make any health care decision on behalf of a patient in a hospital or nursing home, including decisions to withdraw or withhold life-sustaining treatment.

The Legal Basis for the MOLST Process

In 2005, the Public Health Law was amended to give DOH authority to issue "alternative forms" for issuing non-hospital orders not to resuscitate in Monroe and Onondaga Counties. This established MOLST as a pilot program. In 2006, the law was amended to allow such "alternative forms" to be used to issue non-hospital do not intubate (DNI) orders. This was necessary because the Public Health Law makes a distinction between a DNR order and a DNI order. Under the letter of New York's Law, a DNR order only applies when a patient is in cardiac or respiratory arrest, i.e., when a patient has no pulse and/or is not breathing. Even if a patient has a non-hospital DNR order, emergency medical services personnel will still intubate a patient who has a pulse or is breathing, unless the patient also has a non-hospital DNI order.[23] In 2008, the law was amended to authorize MOLST as a non-hospital DNR and DNI order statewide.[24] MOLST is the only authorized mechanism in New York to put in place a non-hospital order that includes both DNR and DNI.[25]

Life-Sustaining Treatment Orders and MOLST Under FHCDA

Chapter 8 of the Laws of 2010, the legislation that included FHCDA (PHL Article 29-CC), made significant changes to the process for consenting to DNR orders and other orders to withhold or withdraw life-sustaining treatment. In addition to authorizing surrogate decision making in general hospitals and nursing homes for any type of health care decision, including DNR orders, it also amended PHL Article 29-B (the old DNR law) to make it applicable only to DNR decisions in certain mental hygiene facilities. It also moved the provisions for non-hospital DNR orders to a new PHL Article 29-CCC.

Under current law, the legal requirements for issuing medical orders to withhold or withdraw life-sustaining treatment differ depending on the patient, the decision-maker, and the setting where the patient is located. These requirements can be divided into eight different categories:

1. Adult Patients with Medical Decision-Making Capacity (Regardless of Setting)

Adults are presumed to have capacity to make medical decisions, unless a contrary determination has been made by a court or by the requisite health care professionals pursuant to FHCDA.[26] Adults with medical decision-making capacity have a right to consent to or decline life-sustaining treatment.[27] Prior to the enactment of FHCDA, there was a therapeutic exception to the rule that a DNR order for a patient with capacity must be based upon the patient's consent. FHCDA eliminated that exception.[28]

As explained above, adults with capacity also have the right to execute advance directives, such as a living will, to avoid getting life-sustaining treatment that they do not want after they lose capacity. A living will may not be fully effective in accomplishing this goal, because a living will may not be written with sufficient specificity to provide clear and convincing evidence of the patient's wishes. In order to provide greater assurance that their wishes will be carried out, patients can consent to medical orders for life-sustaining treatment. With the informed consent of the patient, the patient's physician can issue a variety of medical orders using DOH's MOLST form—from provide comfort measures (palliative care) only; do not attempt resuscitation (allow natural death); do not intubate (DNI); do not hospitalize; no feeding tube; no IV fluids, do not use antibiotics; to no limitations on medical interventions. Physicians may also issue other medical orders related to other life-sustaining treatments (e.g., dialysis) in the space on the form available for "other instructions."

Under FHCDA, surrogate consent is not required if the decision was expressed by the patient before the patient lost capacity "either orally during hospitalization [including during residency in a nursing home] in the presence of two witnesses eighteen years of age or older, at least one of whom is a health or social services practitioner affiliated with the hospital, or in writing."[29] The phrase "in writing" includes any legally executed non-hospital DNR order or MOLST form, even if the form was completed prior to hospitalization with the oral consent of the patient to just one witness who was the attending physician who signed the order(s).[30] However, two witnesses are recommended.

2. Adult Patients Without Medical Decision-Making Capacity Who Have a Health Care Proxy (Any Setting)

A patient without medical decision-making capacity is still presumed competent to appoint a health care agent, unless such person has been adjudged incompetent or otherwise adjudged not competent to appoint a health care agent, or unless a committee or guardian of the person has been appointed under the Mental Hygiene Law or Surrogate's Court Procedure Act (SCPA).[31]

The health care agent named in the health care proxy can consent to medical orders relating to life-sustaining treatment. If the patient's wishes are reasonably known, the health care agent must make decisions in accordance with those wishes. When there is evidence of the patient's wishes, the health care agent should still be asked to consent to the medical orders and given the opportunity to provide additional evidence of the patient's wishes. So long as the health care agent represents that he or she is acting in accordance with the patient's wishes, the health care provider should generally follow the decisions of the health care agent, unless a court has determined otherwise under PHL section 2991.

Under current law, if the principal's wishes regarding the administration of artificial nutrition and hydration are not reasonably known and cannot with reasonable diligence be ascertained, the health care agent does not have authority to make decisions regarding these measures. Health care providers may presume that patients' wishes regarding the administration of artificial nutrition and hydration are reasonably known when health care proxies state that the patients have discussed their wishes with their health care agents, and the agents know their wishes about artificial nutrition and hydration. Even if the patient's wishes regarding artificial nutrition and hydration are not known, the person named as health care agent may still have authority to make the decision as a FHCDA surrogate. It is likely that the health care agent is also highest in priority on the FHCDA surrogate list or could be designated as surrogate by a person higher in priority.[32]

Health care agents can consent to decisions to withhold or withdraw life-sustaining treatment in any setting and therefore have authority to consent to the medical orders on a MOLST form no matter where the form is completed.

3. Adult General Hospital or Nursing Home Patients Without Medical Decision-Making Capacity Who Do Not Have a Health Care Proxy, and Decision Maker Is FHCDA Surrogate

Decisions to withhold and withdraw life-sustaining treatment in a general hospital or nursing home are governed by FHCDA. Unlike PHL Article 29-B, FHCDA does not explicitly state that patients are presumed to consent to life-sustaining treatment.[33] However, FHCDA requires a number of conditions to be satisfied before life-sustaining treatment may be withheld or withdrawn. These include patient-centered decision-making standards for surrogates and clinical standards that must be verified by two physicians.[34] Unless these conditions are satisfied, life-sustaining treatment, including cardiopulmonary resuscitation (CPR), presumably must be provided.[35]

Under FHCDA, the rules for issuing orders to withhold or withdraw life-sustaining treatment in general hospitals or nursing homes have changed in a number of ways. As noted above, FHCDA authorizes surrogate decision making for all medical decisions, not just DNR decisions. Surrogate consent to a DNR order is now governed by the FHCDA rules for decisions to withhold or withdraw life-sustaining treatment. Before FHCDA, a surrogate could consent to a DNR order if the patient had a "terminal condition," which was defined as "an illness or injury from which there is no recovery, and which reasonably can be expected to cause death within one year." By contrast, FHCDA requires "an illness or injury which can be expected to cause death within six months, whether or not treatment is provided." FHCDA like the prior law, also allows surrogate consent when the patient is permanently unconscious. Under prior law, a surrogate could consent to a DNR order if resuscitation would be "medically futile," but FHCDA contains no equivalent standard for surrogate decision making. Before FHCDA, a surrogate could consent to a DNR order when resuscitation would impose an "extraordinary burden on the patient in light of the patient's medical condition and the expected outcome of resuscitation for the patient." The parallel provision of FHCDA is that "the provision of treatment would involve such pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances *and the patient has an irreversible or incurable condition*" (emphasis supplied).[36]

Since it is no longer sufficient that resuscitation is an extraordinary burden, and the patient must also have "an irreversible or incurable condition" under the extraordinary burden standard, hospitals and nursing homes will have to determine whether any of a patient's conditions can be considered "irreversible or incurable." Presumably, this term was not intended to include conditions that are literally irreversible and incurable, but are in no way debilitating. On the other hand, consider the patient who is over 100 years old and has lost medical decision-making capacity, but has no "irreversible or incurable" condition (other than the frailty that naturally accompanies old age). The application of the law to this patient is not entirely clear.

Although the law defines CPR as a type of life-sustaining treatment, it distinguishes between DNR and other orders to withdraw or withhold life-sustaining treatment, in certain circumstances. One significant difference between DNR orders and other orders to withhold or withdraw life-sustaining treatment in FHCDA is that ethics committee review is not automatically required to issue a DNR order in a nursing home under the "irreversible and incurable condition" standard, whereas ethics review committee approval is required in a nursing home to issue other orders to withhold or withdraw life-sustaining treatment under that standard.[37]

4. Adult General Hospital or Nursing Home Patients Without Medical Decision-Making Capacity Who Do Not Have a Health Care Proxy, and for Whom No FHCDA Surrogate Is Available

In limited cases, facilities may withhold or withdraw life-sustaining treatment from patients who lack medical decision-making capacity, have no health care agent, and for whom no surrogate is available. In these cases, treatment is being withheld or withdrawn without consent. A court of competent jurisdiction may make this decision. Alternatively, FHCDA provides that the facility may withhold or withdraw life-sustaining treatment if the decision is consistent with the patient's wishes, if known, or in the patient's best interests, and two physicians determine that treatment "offers the patient no medical benefit because the patient will die imminently, even if the treatment is provided," and "the provision of life-sustaining treatment would violate accepted medical standards."[38] Before FHCDA, a general hospital or nursing home could issue a DNR order for a patient for whom no surrogate was available if CPR was "medically futile," a term that does not appear in FHCDA. Although the law now uses different words, there are probably few, if any, cases in this fourth category where a DNR order legally could have been issued before FHCDA but could not be issued under FHCDA.

5. Adult Patients Outside of a General Hospital or Nursing Home Without Medical Decision-Making Capacity Who Do Not Have a Health Care Proxy (Except Patients in Categories Seven and Eight)

Non-hospital DNR and DNI orders are now governed by the new PHL Article 29-CCC, which is derived from former PHL section 2977.[39] One difference between PHL Article 29-CCC and former PHL section 2977 is that now home care services agencies and hospices are explicitly required to honor non-hospital DNR and DNI orders. A non-hospital DNR order may be issued on the "standard form," which is DOH-3474, or the "alternative form," which is DOH-5003 (the MOLST form).[40] Non-hospital DNI orders can only be issued on the MOLST form, not on the standard form.

FHCDA surrogates have authority to consent to non-hospital DNR and DNI orders.[41] They do not have legal authority to consent to other orders to withhold or withdraw life-sustaining treatment outside of a general hospital or nursing home. Nevertheless, DOH allows the issuance of other orders to withhold or withdraw life-sustaining treatment based upon clear and convincing evidence of the patient's wishes. This is based on patients' common law and constitutional rights, as recognized in case law,[42] as well as the federal statutory right to self-determination.

6. Minor Patients

FHCDA defines a minor as an unmarried individual under eighteen years of age.[43] In general, a parent or legal guardian may consent to medical services for a minor.[44] Under PHL section 2504 and common law, parents can consent to medical orders issued by a physician that withhold or withdraw life-sustaining treatment from their children.[45] Some attorneys may be concerned that a decision to withhold or withdraw life-sustaining treatment from a terminally ill child could be construed as neglect under the Family Court Act. However, in cases involving terminally ill children and burdensome medical interventions, courts have considered parental consent to a physician's order to withhold or withdraw life-sustaining treatment, while providing palliative care to optimize the child's quality of life, a reasonable decision, not an abandonment or medical neglect of the child.[46] Indeed, the New York State Legislature has recently affirmed the legitimacy of palliative care in appropriate circumstances.[47]

FHCDA provides specific procedures that must be followed when a parent or guardian of a minor makes decisions about life-sustaining treatment in a general hospital or nursing home. Most of the provisions for a health care decision for an adult patient by a surrogate also apply to a decision by a parent for a child who lacks capacity, except that the decision only takes into account the child's wishes as appropriate under the circumstances. The attending physician must determine whether the minor has capacity, and if so, the minor must consent to the decision. Only one parent's consent is required, but health care providers must make diligent efforts to notify a second parent who has maintained substantial and continuous contact with the minor.[48] The second parent so notified has an opportunity to object to the decision before it is implemented.[49]

FHCDA does not address parental consent to the withholding or withdrawing of life-sustaining treatment outside of the hospital and nursing home settings. However, the common law provides some guidance. Before the enactment of FHCDA, in *Matter of AB*,[50] the court held that the most relevant statute should govern decisions by parents to withhold or withdraw life-sustaining treatment from minor children. Accordingly, the court applied the standards in section 1750-b of the Surrogate's Court Procedure Act, which governs surrogate decision making for persons with developmental disabilities. Now that FHCDA provides a statutory framework for decisions made by parents for children in general hospitals and nursing homes, that framework should be applied to decisions on behalf of children in the community. Just as *Matter of AB* used the standards in SCPA section 1750-b, the most relevant statute in effect at that time, decisions by parents or legal guardians of minors in the community to withhold or withdraw life-sustaining treatment should incorporate the FHCDA procedures and standards. Thus, physicians should only issue orders to withhold or withdraw life-sustaining treatment from children in the community under circumstances in which those orders would be permitted in nursing homes or hospitals.

Since the standards for nursing homes are the most stringent (specifically regarding the need for ethics committee review when decisions other than DNR are made for a patient who is neither terminally ill nor permanently unconscious), those standards should be used in the community as well. Note that in cases where ethics review committee review is needed in the community, the physician will have to find an ethics review committee willing to review the case even though the patient is neither a hospital inpatient nor a nursing home resident. In these cases, the physician would presumably have privileges at a local hospital, and that hospital's ethics review committee may be willing to review the case.

FHCDA also gives an "emancipated minor" authority to decide about life-sustaining treatment in a general hospital or nursing home.[51] An emancipated minor is a minor who is the parent of a child or is age 16 or older and living independently.[52] Although there are other instances in which a minor may consent to health care without a parent's permission or knowledge, neither FHCDA nor any other New York statute gives minors living independently general authority to make health care decisions for themselves. Also, it should be noted that FHCDA does not allow surrogates on the surrogate list to make decisions for emancipated minors who lack capacity; it only provides for health care decisions for adult patients by surrogates. Under FHCDA, however, a person under 18 years old who is married is an "adult."[53]

7. Patients with a Developmental Disability Who Lack Decision-Making Capacity and Who Do Not Have a Health Care Proxy

FHCDA does not apply to decision making for patients with developmental disabilities who lack medical decision-making capacity. Surrogate decision making for patients with developmental disabilities who lack capacity is governed by the Surrogate's Court Procedure Act (SCPA).[54] Decisions to withhold or withdraw life-sustaining treatment may be made by surrogates as provided in SCPA section 1750-b and 14 NYCRR section 633.10. Decisions by surrogates pursuant to the SCPA may be recorded in the MOLST form.[55] To assure compliance with this process, OPWDD requires that a special checklist be attached to the MOLST form.

8. Patients in a Psychiatric Unit of a General Hospital or a Psychiatric Institution Licensed by OMH Without Decision-Making Capacity Who Do Not Have a Health Care Proxy

FHCDA applies to patients with mental illness in a "general hospital," as defined by FHCDA. FHCDA, however, does not apply to decision making for patients in a ward, wing, unit or other part of a general hospital operated for the purpose of providing services for persons with mental illness pursuant to an operating certificate issued by OMH or a "hospital" as defined in Mental Hygiene Law section 1.03(10). DNR orders for such patients are still governed by the provisions of PHL Article 29-B.[56] In compliance with Article 29-B and any other applicable laws, MOLST may be used for patients with mental illness in any setting.[57]

Legal Requirements Checklists

As described above, decision-making standards and procedures for decisions to withhold or withdraw life-sustaining treatment vary depending on who makes the decision and where the decision is made. Accordingly, DOH has developed checklists that summarize these requirements in six different scenarios, along with general instructions and a glossary:

- MOLST Checklist 1—Adult with capacity (any setting)
- MOLST Checklist 2—Adult with health care proxy (any setting)
- MOLST Checklist 3—Adult with FHCDA surrogate (hospital and nursing home)
- MOLST Checklist 4—Adult without FHCDA surrogate (hospital or nursing home)
- MOLST Checklist 5—Adult without capacity in the community
- MOLST Checklist for Minor Patients and Glossary (any setting)

These checklists are not mandatory; they are intended as a tool to assist health care providers in complying with the complex laws governing decisions concerning life-sustaining treatment when completing MOLST forms.[58]

In addition, OPWDD has developed a checklist for people with developmental disabilities who lack medical decision-making capacity and do not have a health care proxy.[59] This checklist is mandatory and must be attached to the MOLST form. The use of this checklist assures that any medical decisions involving the withholding or withdrawing of life-sustaining treatment from individuals with developmental disabilities comply with the process set forth in the Surrogate's Court Procedure Act.

The DOH checklists for adults share a number of common elements. For example, they remind providers to ask patients about executing a health care proxy, if the patient has not done so and has capacity to execute one. DOH Checklists 2 through 5 set forth the appropriate process for the capacity determination, depending on whether a health care agent or an FHCDA surrogate is the decision-maker. And, they direct the physician to notify the patient of the determination of incapacity if there is any indication that the patient is able to comprehend the determination. All summarize the statutory standards for medical decision-making capacity and informed consent to life-sustaining treatment orders. And, all of the checklists remind providers of the witness requirements and the need to notify the director of the patient's correctional facility or mental hygiene facility and Mental Hygiene Legal Services, where applicable.

The DOH checklists also specify the unique requirements applicable to specific decision-makers and settings. For example, Checklist 2 (for adults with a health care proxy) alerts the provider to the two-physician capacity determination process for decisions by health care agents. It also points out the limits on the health care agent's ability to consent to the withholding or withdrawal of artificial hydration or nutrition. Checklist 3 includes both the patient-centered standards and clinical standards that must be met under FHCDA to justify the withholding or withdrawal of life-sustaining treatment when a surrogate makes that decision. Checklist 3 also points out the required ethics committee determination for decisions to withhold or withdraw life-sustaining treatment (other than CPR) in a nursing home under the "irreversible or incurable condition" standard. Checklist 4 sets forth the two alternative processes for decisions to withhold or withdraw life-sustaining treatment from a patient who lacks capacity and has neither a health care agent nor an FHCDA surrogate: (i) a court proceeding; or (ii) a determination by two physicians that treatment offers the patient no medical benefit because the patient will die imminently, even if the treatment is provided, and the provision of life-sustaining treatment would violate accepted medical standards.

DOH Checklist 5 delineates in detail the complex requirements for adults in the community who lack capacity and do not have a health care proxy. Checklist 5 makes clear that the authority of the FHCDA surrogate in the community is limited to DNR/DNI decisions. It also indicates that decisions concerning other life-sustaining treatment may be made based on clear and convincing evidence of the patient's wishes. "Clear and convincing evidence" is defined in the glossary accompanying the general instructions.[60]

Finally, the DOH checklist for minor patients applies to patients under age 18 who are not married. However, it also notes that special considerations and requirements apply to decisions concerning life-sustaining treatment for emancipated minors. The checklist does not go into detail about the various considerations that apply to life-sustaining treatment decisions by or concerning emancipated minors. Instead, it directs physicians to consult with counsel regarding such decisions. As discussed above, the checklist for minor patients imports into the community setting the FHCDA requirements for withholding or withdrawing life-sustaining treatment, other than DNR, in a nursing home. It requires ethics committee review for such decisions, if the patient is neither terminally ill nor permanently unconscious. The checklist sets forth the requirements to assess the minor's capacity and secure his or her consent, if he or she has capacity. It also describes the requirements concerning notification and participation of a non-consenting parent.

It is undoubtedly challenging for busy health care providers to juggle all of these different checklists with disparate requirements. However, the checklists merely reflect the complexity of the law. And, that complexity is largely driven by a desire to protect the rights of vulnerable patients—a paramount consideration in our society. Clearly, health care providers should appreciate and consider the legal and ethical implications when issuing an order to "allow natural death."

Conclusion

MOLST and FHCDA together provide an opportunity to honor the wishes of patients and to improve the quality of end-of-life care. Widespread completion of health care proxies and MOLST forms by patients with capacity will reduce the need for decision making by FHCDA surrogates for patients approaching the end of life and will provide guidance for surrogates when needed. MOLST empowers patients in two ways. It provides a structured framework for discussions between clinicians and patients and their families about end-of-life options, so that patients have the information they need to make informed decisions. And, it provides a vehicle for patients to make clear their wishes concerning life-sustaining treatment. MOLST enables patients to communicate across care settings their desire to receive life sustaining treatment. It also makes it possible to honor the wishes of a patient to spend his or her last days comfortably at home, instead of in a hospital receiving futile and invasive interventions.

Endnotes

1. *See* 42 U.S.C. §§ 1395cc(f), 1396a(w).
2. Kass-Bartelmes, BL, Hughes, B, "Advance Care Planning: Preferences for Care at the End of Life," Agency for Healthcare Research and Quality, March 2003.
3. According to a 1999 Harvard Public Opinion Poll, 71 percent of Americans would prefer to die at home. A 2002 Harris Interactive Poll found that 86 percent of Americans believe that people who have a terminal illness would most like to receive end-of-life care at home. See also Yankelovich Partners/TIME/CNN Survey, available at http://www.libraryindex.com/pages/3165/Public-Opinion-About-Life-Death-CONCERNS-ABOUT-DEATH.html.
4. Angus, DC, Barnato, AE, Linde-Zwirble, WT, Weissfeld, LA, Watson, RS, Rickert, T, Rubenfeld, GD, "Use of intensive care at the end of life in the United States: An epidemiologic study," *Critical Care Medicine*, 32(3):638-643, March 2004. Zhao, Y, Encinosa, W, "The Cost of End-of-Life Hospitalizations 2007," HCUP Statistical Brief #81, Agency for Healthcare Research and Quality, Nov. 2009, http://www.hcup-us.ahrq.gov/reports/statbriefs/sb81.pdf.
5. Centers for Disease Control and Prevention, Nation Vital Statistics System, Deaths by place of death, age, race, and sex: United States, Worktable 309, 2005, available at: http://www.cdc.gov/nchs/nvss/mortality/gmwk309.htm.
6. Dartmouth Atlas on Health Care, End of Life Care, http://www.dartmouthatlas.org/data/region/profile.aspx?loc=34&tab=22.
7. Goodman, DC, Fisher, ES, Chang, CH, Morden, NS, Jacobson, JO, Murray, K, Miesfeldt, S, "Quality of End-of-Life Care for Medicare Beneficiaries, Regional and Hospital-Specific Analyses," Dartmouth Atlas Project, Nov. 2010, at 4.
8. *Id.* at 28.
9. L. of 2010, ch. 8, § 2.
10. "Advance Directives and Advance Care Planning: Report to Congress," U.S. Dept. of Health and Human Services, Aug. 2008, at 14, citing Brock, D, Foley, DJ. "Demography and Epidemiology of Dying in the U.S. with Emphasis on Deaths of Older Persons," in Harold, JK, Lynn, J, eds., *A Good Dying: Shaping Health Care for the Last Months of Life*, NY, NY: 1998, at 49-60.
11. *Id.* at 42.
12. Oregon State Health & Science University, Center for Ethics in Health Care, POLST, http://www.ohsu.edu/polst/.
13. Hickman, SE, Nelson, CA, Perrin, NA, Moss, AH, Hammes, BJ, Tolle, SW, "A Comparison of Methods to Communicate Treatment Preferences in Nursing Facilities: Traditional Practices Versus the Physician Orders for Life-Sustaining Treatment Program," *Journal of the American Geriatrics Society*, 58(7): 1241-1248, Jul. 2010; Hammes, BJ, Rooney, BL, Gundrum, JD, "A Comparative, Retrospective, Observational Study of the Prevalence, Availability, and Specificity of Advance Care Plans in a County that Implemented an Advance Care Planning Microsystem," *Journal of the American Geriatrics Society*, 58(7): 1249-1255, Jul. 2010; Hickman SE, Nelson CA, Moss AH et al., "Use of the Physician Orders for Life-Sustaining Treatment (POLST) Paradigm Program in the Hospice Setting," *J Palliat Med.* 12:133–141, 2009.
14. As discussed more fully below, if the patient lacks medical decision-making capacity, an appropriate FHCDA surrogate can provide consent to MOLST orders, based on specified standards, on behalf of a patient in a hospital or nursing home. In the community, surrogates may consent only to DNR and DNI orders.
15. Information for providers and consumers concerning the MOLST process is available on the Department of Health's website at http://www.nyhealth.gov/professionals/patients/patient_rights/molst/ and on the Compassion and Support website at http://www.compassionandsupport.org/index.php.
16. PHL § 2994-ff (orders pertaining to a patient admitted to a mental hygiene facility are governed by Article 29-B).
17. PHL §§ 2994-l, 2994-ff.

18. PHL § 2994-l(2).
19. *See* PHL §§ 2964, 2994-d(3)(a)(ii), 2994-cc(1).
20. *Matter of Westchester County Med. Ctr. on Behalf of O'Connor*, 72 NY2d 517.
21. PHL § 2982(2).
22. *Id.*
23. DOH Bureau of Emergency Medical Services Policy 11-02 (http://www.nyhealth.gov/nysdoh/ems/pdf/11-02.pdf).
24. L. 2008, ch. 197.
25. PHL § 2994-dd(6).
26. PHL § 2994-c(1).
27. *Matter of Storar*, 52 NY2d 363, 376.
28. *Cf.*, former PHL section 2964(3), repealed by l. 2010, ch. 8, § 9. The legislature intended to prohibit health care providers from issuing DNR orders without the informed consent of the patient, and PHL section 2805-d(4)(d) should not be interpreted to allow the "therapeutic exception." L. 2010, ch. 8 did not eliminate the principle that patients are presumed to consent to the administration of CPR in the event of cardiac or respiratory arrest. *See* PHL § 2962(1).
29. PHL § 2994-d(3)(a)(ii).
30. *See* PHL § 2994-cc(1).
31. PHL § 2981(1).
32. *See* PHL § 2994-d(1).
33. *Cf.*, PHL § 2962(1).
34. The patient-centered standards require that decisions are made "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…in accordance with the patient's best interests." The patient's best interests include: "consideration of the dignity and uniqueness of every person; the possibility and extent of preserving the patient's life; the preservation, improvement or restoration of the patient's health or functioning; the relief of the patient's suffering; and any medical condition and such other concerns and values as a reasonable person in the patient's circumstances would wish to consider." PHL § 2994-d(4). The clinical standards require a determination that (i) treatment would be an extraordinary burden, and either the patient has a terminal condition that is expected to cause death within six months, regardless of whether treatment is given, or the patient is permanently unconscious; or (ii) the treatment would be inhumane or extraordinarily burdensome and the patient has an irreversible or incurable condition. PHL § 2994-d(5).
35. *See* PHL § 2994-d; see also, PHL §§ 2805-d(2), 2504(4), 3000-a, and generally Article 30.
36. PHL § 2994-d(5).
37. PHL § 2994-d(5)(b).
38. PHL § 2994-g(5).
39. Former PHL § 2977 was repealed by l. 2010, ch. 8, § 20.
40. *See* PHL § 2994-dd(2) and 2994-dd(6).
41. PHL § 2994-cc(3).
42. *Cruzan v. Director, Missouri Dept. of Health*, 497 US 261; *Matter of Storar*, 52 NY2d 363.
43. PHL § 2994-a.
44. PHL § 2504.
45. *Matter of AB by Her Mother, CD*, 196 Misc.2d 940, 959 ["Pursuant to *Matter of Hofbauer* and Public Health Law § 2504(2), CD is authorized to make this choice for her daughter"]). Unlike former PHL section 2977, PHL section 2994-cc contains no specific provisions regarding consent by a parent to a nonhospital DNR order for a minor child. There is nothing, however, in the legislative history of l. 2010, ch. 8, to suggest any intent to take away the ability of the parent or legal guardian of a minor to consent to a nonhospital DNR order for a minor.
46. *See Matter of Hofbauer*, 47 NY2d 648, 656.
47. *See* l. 2010, ch. 331, adding PHL § 2997-c.
48. PHL §§ 2994-a(24), 2994-e.
49. PHL §§ 2994-a(26), 2994-m(2)(a).
50. 196 Misc.2d 940, 959.
51. PHL § 2994-e(3).
52. PHL § 2994-a(8).
53. PHL § 2994-a(1).
54. PHL § 2994-b(3).
55. Memo from Eileen Zibell to DDSO Directors, Voluntary Provider Agency Executive Directors regarding approval of MOLST form (January 21, 2011), http://www.omr.state.ny.us/health/hp_MOLST.jsp.
56. PHL §§ 2961(9), 2994-a(10).
57. Letter from Commissioner Michael Hogan, NYS Office of Mental Health, to Commissioner Richard Daines, NYS Dept. of Health (August 23, 2010), http://commons.wikimedia.org/wiki/File:MOLST_OMH_approval.JPG.
58. The checklists are available on the DOH website at: http://www.nyhealth.gov/professionals/patients/patient_rights/molst/.
59. The OPWDD checklist is available at: http://www.omr.state.ny.us/health/hp_MOLST.jsp.
60. "Clear and convincing evidence" is evidence that the patient held a firm and settled commitment to the withholding of life-sustaining treatment in the event of circumstances like the patient's current medical condition. The evidence may be in a written living will, and/or previous oral statements indicating the patient's wishes, considering the circumstances under which such statements were made and to whom. In order to decide whether the evidence of the patient's wishes is clear and convincing, consideration should be given to:
    - whether the statements were general or specific;
    - whether the statements were about specific circumstances (for example, terminal illness, persistent vegetative state) that are similar to the patient's current medical condition;
    - the intensity, frequency, consistency, and seriousness of such statements;
    - whether the statements tended to show that the patient held a firm and settled commitment to certain treatment decisions under circumstances like those presented;
    - whether the strength and durability of the patient's religious and moral beliefs make a more recent change of heart unlikely; and
    - whether the statements were made to one person only or to more than one person close to the patient.

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