FAQ HTML

FREQUENTLY ASKED QUESTIONS ABOUT THE FAMILY HEALTH CARE DECISIONS ACT

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Introduction

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The first set of Q&A's were posted the first week of June 2010. Q&A's that were later added or revised are dated.

Contents

I. Definitions (PHL § 2994-a)

1. Q - Adult - The FHCDA defines "Adult" to mean "any person who is eighteen years of age or older or has married," but the Health Care Proxy Law and other laws also regard a person as an adult if the person is the parent of a child. Why is the FHCDA definition of adult different?

A - The Task Force that developed the FHCDA proposal reasoned that just because a minor -- perhaps even a 13 or 14 year old -- is the mother or father of a child, does not mean that the minor has the capacity or maturity to decide on their own about whether to forgo life-sustaining treatment. Accordingly, the FHCDA does not treat a minor parent as an "adult", but rather as an "emancipated minor." As such, the minor can consent to treatment on par with an adult, but a decision to forgo life-sustaining treatment would require approval of an Ethics Review Committee. (Revised September 8, 2010.)

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2. Q - Attending physician - Can a resident be an "attending physician" for purposes of the FHCDA?

A. Neither the Department of Health nor the State Education Department have addressed this. But it seems likely that a resident practicing under a limited permit (Ed. Law §6526) can act as an attending physician for FHCDA purposes. It seems less likely that a resident or intern practicing under a licensing exemption (Ed. Law §6528) can act as an attending physician for FHCDA purposes. (Added September 8, 2010)

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3. Q - Close friend - How does the FHCDA definition differ from the definition in the former DNR Law?

A - The FHCDA simply requires the close friend to sign a statement; the former DNR Law required the close friend to sign an affidavit (i.e. a statement sworn before a notary). Also the FHCDA makes it clear that the term could include a relative who is not close enough to be on the surrogate list.

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4. Q - Domestic partner - Where did the definition of "domestic partner" come from?

A - It is substantially similar to the definition that is in PHL 4201, which gives the domestic partner of a deceased person the right to make decisions regarding disposition of the deceased person's remains.

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5. Q - Health care - The definition says that "Providing nutrition or hydration orally, without reliance on medical treatment, is not health care under this article and is not subject to this article." What does "Providing nutrition or hydration orally, without reliance on medical treatment" refer to, and what is the purpose of the phrase?

A - The phrase "providing nutrition or hydration orally, without reliance on medical treatment" simply refers to feeding a patient, i.e., giving the patient food or drink to swallow. So the FHCDA applies to surrogate decisions regarding the provision of nutrition and hydration by tubes placed in the patient's nose, stomach, intestines or arms; but it does not apply to decisions regarding giving a patient food or drink to swallow.

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6. Q - Health or social service practitioner - This definition includes certain licensed health care professionals (i.e., a registered professional nurse, nurse practitioner, physician, physician assistant, psychologist or licensed clinical social worker) but only if the professional is "acting within his or her scope of practice." A later section says that such professionals can provide the required concurring determination regarding a patient's decisional capacity. Is that determination within the scope of practice of such professionals?

A - The State Education Department Office of Professions, in an informal response to this question from the Department of Health, indicated any registered professional nurse, nurse practitioner, psychologist or licensed clinical social worker can concur (or not concur) with an attending physician's capacity determination within their scope of practice. DOH has not yet issued a statement regarding the scope of practice for physician assistant. Note that hospitals and nursing homes must adopt written policies identifying the training and credentials of health or social services practitioners qualified to provide concurring determinations in their facilities. Also, just because something is within the scope of practice, the practitioner is not necessarily competent to do it.

Also, as a result of a 2017 amendment, an "attending nurse practitioner" can make an initial determination of incapacity, as well as a concurring determination (though not for the same patient), *Added 12/28/18).*

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7. Q - Life-sustaining Treatment - Why does the FHCDA definition of life-sustaining treatment include the statement that "For the purpose of this article, cardiopulmonary resuscitation is presumed to be life-sustaining treatment without the necessity of a determination by an attending physician."?

A - The FHCDA allows a surrogate to make decisions about the withholding or withdrawal of life-sustaining treatment. The statement about resuscitation makes it clear that such authority includes the authority to make decisions about the withholding or withdrawal of resuscitation - that is, to consent to a do-not-resuscitate order.

II. Applicability; priority of certain other surrogate decision-making laws and regulations. (PHL § 2994-b)

1. Q - Why does the FHCDA apply only in specified settings (currently, in hospitals, nursing homes and hospice)?

A - Initially, the FHCDA applies only in hospitals and nursing homes, where there would be greater oversight and safeguards. However, based on recommendations by the Task Force on Life and the Law, the FHCDA was amended (i) in 2011 to apply decisions regarding hospice care for incapable patients with surrogates and (ii) in 2015 to decisions regarding hospice care for incapable patients without surrogates.

The Task Force recommended extending the FHCDA further to apply: (i) to other DOH licensed settings such as home health care and ambulatory surgery centers; and (ii) to decisions for patients with intellectual disabilities and who are in or transferred from psychiatric hospitals and units.

(Revised 12/28/18.)

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2. Q - Would the FHCDA apply in an off-campus clinic operated by a hospital?

A - Yes. An "extension clinic" is considered part of the general hospital. (Added September 8, 2010)

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3. Q - What is a court-appointed guardian under Surrogate's Court Procedure Act (SCPA) Article 17-A and why does the FHCDA not apply to persons who have such guardian?

A - SCPA Article 17-A creates a process for the court appointment of a guardian for an adult with an intellectual disability. Such guardian has the authority to make health care decisions, including decisions about life-sustaining treatment, under rules and principles set forth in that article.

(Revised 12/28/18.)

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4. Q - What is SCPA §1750-b, and why does the FHCDA not apply to persons described in that section for decisions to withdrawal life-sustaining treatment?

A - SCPA §1750-b is a section in SCPA Article 17-A that allows a family member, close friend, or surrogate decision-making panel, without being appointed as guardian by the court, to make a decision about life-sustaining treatment for a person with intellectual disability who meets certain clinical criteria.

While there was debate whether SCPA §1750-b or the FHCDA should apply to such decisions, the Legislature decided to let SCPA Article §1750-b continue to apply. However, it directed the Task Force on Life and the Law to form a subcommittee to recommend whether the FHCDA rather than SCPA §1750-b should apply to such persons. In 2017, the Task Force approved the report of a Special Advisory Committee that recommended repealing SCPA Article 17-A, and extending the FHCDA, with some amendments, to decisions for persons with intellectual disabilities.

(Revised 12/28/18.)

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5. Q - The FHDCA says that it does not apply when consent to treatment is governed by "the mental hygiene law or regulations of the office of mental health (OMH) or the office of mental retardation and developmental disabilities" [now the Office for People with Developmental Disabilities - OPWDD) What are those laws and regulations, and when would they ever apply to a hospital or nursing home patient?

A --OPWDD. OPWDD regulations (14 NYCRR §633.11) govern surrogate consent to treatment for residents of OPWDD- operated and licensed facilities. Such regulations would continue to be applicable to a person who was removed to a general hospital or nursing home for treatment, but not discharged from such OPWDD-operated or licensed facility.

OMH regulations (14 NYCRR §27.9 and §527.8) govern surrogate consent to treatment and objection to treatment for patients of OMH-operated and licensed psychiatric hospitals and hospital units. Such regulations would continue to be applicable to person who was removed to a general hospital or nursing home for treatment, but not discharged from such OMH operated or licensed psychiatric hospital or unit.

In contrast, with respect to a person who was admitted to a hospital or nursing home from an OMH-licensed community residence, consent or objection to treatment would be based on the same principles that would apply to any other hospital patient. So if the patient lacked decisionmaking capacity and did not have a health care agent, the FHCDA would govern decisions for the patient. Revised\

(Revised 12/28/18.)

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6. Q - What role does a Mental Hygiene Law Article 80 Surrogate Decision Making Committee (SDMC) have since the FHCDA authorizes surrogate decision-making for hospital and nursing home patients?

A - MHL Article 80 and 14 NYCRR Part 710 authorizes a local SDMC to make treatment decisions for persons with mental disabilities who reside or once resided in an OPWDD, OMH or OASAS facility, or who receive or once received certain OPWDD services, and do not have a family member to make such decisions.

SPCA §1750-b makes the SDMC the decision-maker of last resort for persons with intellectual disabilities for purposes of life-sustaining treatment decisions. As a result, the SDMC is the surrogate of last resort for decisions to withdraw or withhold life-sustaining treatment for hospital or nursing home patients with intellectual disabilities.

OPWDD surrogate decision-making regulations make the SDMC the surrogate of last resort for residents of OPWDD facilities. As a result, the SDMC is also the surrogate of last resort for decisions to consent to treatment for those hospital or nursing home patients for whom OPWDD surrogate decision-making regulations apply.

In addition, SDMC is available, but optional, to provide consent to treatment for decisions in a hospital or nursing home for an eligible person when OPWDD regulations and SCPA §1750-b do not apply.

Finally, the SDMC continues to have the same role that it currently has for treatments provided outside of a hospital, nursing home or hospice, for eligible persons.

Under 14 NYCRR Part 710, a SDMC for a person with mental illness can refuse major medical treatment. In some cases, this would be withholding life-sustaining treatment.

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7. Q - It is very difficult to identify which surrogate decision-making law applies to hospital or nursing home patients who have developmental disabilities or mental illness. Is there a chart that summarizes this, perhaps with examples?

A - Yes. See the document "Surrogate Decision-Making for Patients With Mental Disabilities: A Chart of Applicable Laws and Regulations", which is linked to the FHCDA Information Center website.

III. Determination of incapacity (§2994-c)

1. Q - Why does this section require the attending physician or attending nurse practitioner to "confirm the adult patient's continued lack of decision-making capacity before complying with health care decisions made pursuant to this article, other than those decisions made at or about the time of the initial determination," what does "confirm" mean, and what does "at or about the time of the initial determination" mean?

A - A patient's ability to make decisions may fluctuate from day to day, and a patient may be capable of making some decisions and not others. Accordingly the FHCDA requires the physician to "confirm" the continued lack of capacity, if a surrogate continues to make decisions on the patient's behalf.

The FHCDA does not impose any standards with respect to confirming incapacity or specify how the determination should be made. Presumably, the determination will require reasonable steps under the circumstances: for a patient who has been in a coma, or who has advanced dementia, it may be as simple as a notation, "incapacity confirmed." For a patient whose capacity has been more fluid, the physician should rely upon his or her judgment about the steps needed to confirm incapacity, and document the basis for the confirmation in the medical record.

"At or about the time" is a necessarily imprecise term, and allows the attending physician to exercise judgment about whether the last determination of incapacity was recent enough to be reliable.

(Revised 12/28/18.)

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2. Q - While the FHCDA allows a concurring determination of incapacity to be made by a health or social services practitioner, the Health Care Proxy Law seems to still requires that a physician provide the concurring determination. Is that correct, and is there a reason for it?

A - That is correct, and while there might be some rationale for the difference (e.g., the FHCDA has other safeguards that the proxy law does not) it seems that this is an instance where the proxy law should be amended to "catch up" with the FHCDA standard for concurring determinations.

3. Q - Can the attending physician or attending nurse practitioner make a determination of capacity, without personally examining the patient, e.g., over the phone?

A - Unlike the prior DNR Law, the FHCDA no longer contains a "personal examination" requirement. As a result the physician only needs to comply with the applicable professional standard of care. In most instances, that would require a personal examination, but in limited circumstances it might not, such as when the patient lacks capacity as a result of being unconscious.

(Revised 12/28/18.)

IV. Health care decisions for adult patients by surrogates (§ 2994-d)

A. Identifying the surrogate

1. Q - Is the "surrogate" a court appointed position?

A - No. It is a person in the highest category on the surrogate list who is available, willing and competent to make decisions for the incapable patient, and is identified when there is no health care agent.

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2. Q - The highest priority is "A guardian authorized to decide about health care" pursuant to MHL Article 81. Does that include a guardian appointed prior to the date the FHCDA became effective?

A - The FHCDA is not explicit about this, but the answer in all likelihood is yes.

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3. Q - When the highest category is an adult son or daughter, and there is more than one such person, are they all surrogates? If not, then who chooses the surrogate, and on what basis?

A - The FHCDA states that "one person" from the list is the surrogate. While the FHCDA does not specify who identifies the surrogate when more than one person is in the highest category, it necessarily will be the responsibility of the hospital or nursing home to identify the surrogate. In most cases, this should be resolved without difficulty - usually the adult sons and daughters can agree upon the surrogate. In other cases it will be apparent to the hospital staff that one of the patient's adult children is best able to speak of the patient's previous wishes and, if the patient's wishes are not known, the patient's best interests. If there is a dispute, efforts should be made to resolve it informally if possible (e.g., through team meetings, ethics consultation or mediation or the hospital ethics process) or else the matter should be referred to the Ethics Review Committee. (Revised September 8, 2010)

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4. Q - What if someone lower down on the surrogate list objects to the decision of the surrogate, how would the hospital respond? For example, would the hospital withdraw treatment from a patient despite objections by the adult child because a domestic partner is higher in priority than the adult child?

A - The hospital should first try to resolve the dispute informally. If it cannot be resolved informally, the hospital should refer the matter to the Ethics Review Committee. If the higher priority person insists upon the provision of life-sustaining treatment, the hospital cannot discontinue such treatment without a court order. In such proceeding, the court will consider whether the surrogate is meeting his or her obligation to make health care 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 with reasonable diligence be ascertained, in accordance with the patient's best interests.

If the surrogate directs the withdrawal or withholding of treatment but a lower priority person insists upon the provision of treatment, the hospital generally should seek judicial review before withdrawing or withholding treatment, although it does not have a legal obligation to do so. If the hospital decides to withdraw the treatment in such circumstance, the hospital should notify the objecting person so that such person could seek judicial review if they were inclined to do so. In such proceeding, the court will consider the same issue described above: whether the surrogate met his or her obligation to make a decision based on the patient's wishes if known, or else best interests. *(Revised September 8, 2010)*

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5. Q - Would the following persons be considered a brother or sister for purposes of the FHCDA surrogate list: A half-brother or half-sister? A step-brother or step-sister? A brother or sister by adoption? Would a full brother or sister have priority over a half-brother or half-sister?

A - A half brother or half sister would be considered a brother or sister. A step-brother or step-sister would not be considered a brother or sister. A brother or sister by adoption would be considered a brother or sister. (Revised September 8, 2010)

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6. Q - Would the following persons be considered a son or daughter: A step-son or daughter? An adopted son or daughter?

A - A step-son or step-daughter would not be considered a son or daughter, unless the step-son or step-daughter were adopted. An adopted son or daughter would be considered a son or daughter. (Revised September 8, 2010)

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7. Q - What is the role of the designated representative (NYCRR 415.10) in a nursing home? Is the designated representative and surrogate one and the same?

A - The designated representative is a person (or persons) designated in accordance with 10 NYCRR 415.2(f) to exercise certain rights on behalf of a nursing home resident who lacks capacity. A person does not have authority to make health care decisions for a resident by virtue of being a designated representative. A surrogate is the person identified in accordance with the FHCDA to make health care decisions for a resident who lacks capacity. The designated representative and the surrogate will in many cases be the same individual, but they are not necessarily the same individual.

B. Authority of surrogate

1. Q - Can the surrogate consent on behalf of a patient to an HIV test under PHL § 2781 be obtained under FHCDA?

A - Yes.

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2. Q - Can a surrogate consent to experimental treatment?

A - Yes, although if the treatment is part of a study, and therefore constitutes human subject research, other considerations apply (see below).

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3. Q - Can the surrogate consent to enrolling the patient in federally-regulated human subject research?

A - Federal human subject research regulations allow consent for incapable patients to be enrolled in research protocols to be given by a "Legally Authorized Representative. " That term is defined in 45 CFR §46.102 to include a person "authorized under applicable law to consent on behalf of a prospective subject to the subject's participation in the procedure(s) involved in the research. Thus the FHCDA would appear to give the surrogate such authority in many cases, although the scope of that authority is uncertain.

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4. Q - Is the surrogate the "personal representative" of the patient under 45 CFR § 164.502(g)(1) ("HIPAA")?

A - Yes, just as a health care agent under a health care proxy is. If the patient lacks capacity, and the surrogate is empowered to make health care decisions, then the surrogate is the "personal representative" under HIPAA.

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5. Q - Is the surrogate a "qualified person" under PHL § 18?

A - No, not necessarily. But the surrogate has a right and duty to be informed about the patient's medical condition, prognosis, diagnosis and the alternatives to the proposed treatment as specified under FHCDA (PHL § 2994-d(3)(c)).

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6. Q - Does a surrogate's decision remain valid even after the patient is discharged from the hospital or nursing home?

A - The FHCDA states that it applies only to decisions regarding health care "provided in a hospital." PHL 2994-b.1. (The term "hospital" is defined to include nursing homes and hospice as well. See PHL §2994-a.17-a). But it would be reasonable to read the FHCDA as governing decisions regarding care that is initially provided in the hospital, but continues after discharge pursuant to the same consent. Thus a surrogate could consent on behalf a hospital patient to a course of chemotherapy that begins during hospitalization.

Also, medical orders issued on the DOH-5003 (MOLST) or DOH-3474 (non-hospital DNR) forms do not have to be re-issued i in settings outside of the hospital, but if the hospital, nursing home or hospice uses another form to withhold life-sustaining treatment, those forms would not apply in other settings (Revised December 28, 2019).

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7. Q - Can a surrogate consent to the patient's discharge from a hospital, and admission to a post-acute care facility or program?

A - The FHCDA authorizes only surrogate decisions regarding health care "provided in a hospital" or nursing home. That would clearly include the decisions regarding admission to and discharge from a hospital or nursing home. But the FHCDA would appear not to govern decisions to admit a patient into other post-acute facilities or programs such as home care or assisted living. Even so, such facilities and programs should be no less willing to accept admission and financial decisions by family members than they were before the FHCDA was enacted. (Added September 8, 2010).

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8. Q - Can a surrogate direct the discharge of a patient against medical advice?

A - The surrogate can make any decision that the patient, if capable could have made, which could include leaving against medical advice. However, the surrogate is obligated to make decisions based on the patient's wishes if known, or else the patient's best interests. So a provider could seek to block a surrogate's decision to remove a patient if the decision was inconsistent with that standard. Moreover, if the discharge involved the withdrawal or withholding of life-sustaining treatment, the provider could also oppose the discharge if the decision did not meet the criteria for the withdrawal or withholding of treatment.

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9. Q - Can a surrogate consent to donation of a patient's organ's after death?

A - No, not by virtue of being surrogate. Consent to organ donation is governed by the state's Uniform Anatomical Gift Act, not the FHCDA. But the UAGA has a decision maker list similar to that in the FHCDA.

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10. Q - Does the FHCDA give the surrogate access to the patient's medical record?

A - Yes. The FHCDA gives the surrogate "the right to receive medical information and medical records necessary to make informed decisions about the patient's health care." Like a health care agent, the surrogate has this right only after it has been determined that the patient lacks capacity and the surrogate's authority to make health care decisions has commenced.

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11. Q - Can a surrogate apply for Medicaid on behalf of an incapable patient?

A - Yes. Federal Medicaid regulations allow a written application from "the applicant, an authorized representative, or, if the applicant is incompetent or incapacitated, someone acting responsibly for the applicant." 42 CFR § 435.907(a). This would seem to include a FHCDA surrogate. (Added September 8, 2010).

C. Prior decision of adult patient

1. Q - What is the purpose of the "prior decision" clause - the provision that states as follows?

(ii) Nothing in this article shall obligate health care providers to seek the consent of a surrogate if an adult patient has already made a decision about the proposed health care, expressed orally or in writing or, with respect to a decision to withdraw or withhold life-sustaining treatment expressed either orally during hospitalization 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.

A - The FHCDA was not intended to impose surrogate-decision-making upon patients who, prior to losing capacity, made their own decision about treatment. Accordingly, the FHCDA provides that there is no need to seek a surrogate decision if the patient made a prior oral or written decision consenting to a treatment.

However, there were concerns about an attending physician withdrawing or withholding life-sustaining treatment without a surrogate decision based only upon information that the patient had at one time verbally stated a wish to forgo such treatment. Accordingly, the FHCDA provides that there is no need to seek a surrogate decision regarding the withdrawal or withholding of life-sustaining treatment only if the patient's prior decision to forgo life-sustaining treatment was made either (i) orally, during hospitalization, and witnessed by two persons, including one health or social services care practitioner, or (ii) in writing.

In cases that do not meet this requirement - i.e., where the patient's oral statements were made prior to hospitalization or nursing home admission or without witnesses -- a surrogate would make the decision. But the surrogate would still be bound to make a decision in accord with what the patient would have chosen.

Note that when a patient arrives at the hospital with a non-hospital DNR order, or a DNR order from another facility, special rules apply. See Q&A#3 below. (Revised September 8, 2010).

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2. Q - What sort of writings and oral statements would suffice, and what sort would not?

A. A patient's prior written or oral consent to the provision of treatment should be adequate to rely upon without seeking a surrogate decision if it reasonably evidences that consent. However, a prior oral or written decision to withdraw or withhold life-sustaining treatment should be sufficiently specific to have met the "clear and convincing evidence" standard before it may be relied upon without seeking a surrogate decision, inasmuch as the clause was not intended to change pre-FHCDA reliability standards for prior decisions by the patient himself or herself. This means that the decision must clearly apply to both the life-sustaining treatment under consideration and the medical circumstances, e.g., terminal illness.

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3. Q - If a patient is admitted to a hospital with a non-hospital DNR order (including a MOLST form), or with a DNR order that was entered at another facility, can that be honored even if the patient had consented to it prior to the current hospitalization?

A - Yes. The provisions governing non-hospital DNR orders and inter-institutional transfers obligate the hospital to honor such orders. Hospital emergency services personnel may disregard a nonhospital order not to resuscitate if they believe in good faith that consent to the order has been revoked, or that the order has been cancelled; or if family members or others on the scene (other than such personnel) object to the order and physical confrontation appears likely; and hospital emergency services physicians may direct that the nonhospital order not to resuscitate be disregarded if other significant and exceptional medical circumstances warrant disregarding the order. If the patient is admitted, the medical orders to withhold life-sustaining treatment remain effective until an attending physician examines the patient, whereupon the attending physician must continue the orders, unless the physician determines that the order is no longer appropriate or authorized. There is no requirement to secure another consent from the surrogate. (Added September 8, 2010).

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4. Q - The FHCDA makes little mention of advance directives. What is the role of a patient's advance directives in this law?

A - As discussed above, a living will, less formal documents and/or oral statements by a patient could provide the basis for the withdrawal or withholding of life-sustaining treatment under the Prior Decision clause, provided it addresses the treatment decision at issue. In addition, while such advance directives might not qualify as a prior decision, they could still provide sufficient evidence of a patient's wishes for a surrogate (or on the case of a patient without a surrogate for the hospital or nursing home) to act based on the patient's known wishes. A health care proxy would still empower a health care agent to make decisions for the patient under the Health Care Proxy Law, and enable the patient to choose the person who will decide about treatment.

5. Q - If a now-incapable patient who has lost capacity left an advance directive, or had made a prior oral statement, that clearly established the patient's desire to not have a certain treatment, can a surrogate still require that the treatment be continued?

A - The short, general answer is that the hospital and attending physician are obligated to honor this patient's clear wishes, although they may opt to seek judicial review before implementing the decision. But this is a sensitive question, and different facts may require different guidance.

The FHCDA provides that when a surrogate directs the provision of life-sustaining treatment, a hospital or physician that "does not wish to provide treatment," must nonetheless comply with the surrogate's decision pending either transfer of the patient to a willing hospital or individual health care provider, or judicial review. PHL § 2994-f.3. But such clause would not seem to be applicable to this case, for at least three reasons: First, the plain language of the clause relates to cases where it is the hospital or physician that does not wish to provide treatment; it should not be read to apply to cases where it is the patient who does not want the treatment. Second, when there is a clear prior decision by the patient, there is no need to designate a "surrogate," and thus there is no surrogate to invoke 2994-f.3. Third, applying the clause to this case might violate a patient's constitutional right to reject unwanted treatment.

In sum, the hospital and provider are obligated to honor this patient's clear wishes. But they retain the option to seek judicial review before implementing the decision. (Added September 8, 2010).

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6. Q - Does the prior decision clause apply to decisions by patients who have capacity?

A - No. Nothing in the FHCDA governs decisions by patients with capacity.

D. Decision-making standard

1. Q - Does a surrogate need clear and convincing evidence of a patient's wishes to make a decision to direct the withdrawal of life-sustaining treatment?

A - No. Indeed, a key purpose of the FHCDA was to eliminate the clear and convincing standard for clinically appropriate end-of-life decisions. Under the FHCDA, the surrogate must make the decision based on the patient's wishes "if reasonably known" or else based on the patient's best interests. There is no requirement that the surrogate specifies on what basis he /she is making the decision for the patient. However, if hospital has reason to believe that the surrogate is not acting in good faith or is making decisions which are clearly contrary to the patient's known wishes or best interests, then the hospital should not necessarily follow the surrogate's decision. It may instead opt to convene its informal mediation, consultation or ethics process, or convene the Ethics Review Committee.

(Revised September 21, 2010)

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2. Q - Do the FHCDA clinical criteria for the withdrawal of life-sustaining treatment apply to the entry of DNR orders? Do they replace the clinical criteria that were in the DNR Law?

A - Yes and yes. For any decision made after June 1, 2010, a surrogate decision to enter a DNR order must be based on the new clinical criteria. In practice, there are unlikely to be many cases where a DNR order could be entered under one law, but not under the other.

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3. Q - Do DNR orders that predate the FHCDA and were based on the former criteria need to be re-issued?

A - They do not have to be re-issued.

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4. Q - The FHCDA provides that a surrogate may consent to the withdrawal of life-sustaining treatment if one of two standards is met. The first standard requires a determination that "treatment would be an extraordinary burden to the patient." Who makes that determination? The surrogate or the attending physician?

A - The statute is not specific on this point, but it appears to be the surrogate, although the surrogate certainly should make such determination in consultation with the physician. The relevant clause states as follows:

5. Decisions to withhold or withdraw life-sustaining treatment. In addition to the standards set forth in subdivision four of this section, decisions by surrogates to withhold or withdraw life-sustaining treatment shall be authorized only if the following conditions are satisfied, as applicable:

(a)(i) Treatment would be an extraordinary burden to the patient and an attending physician determines, with the independent concurrence of another physician, that, to a reasonable degree of medical certainty and in accord with accepted medical standards,

(A) the patient has an illness or injury which can be expected to cause death within six months, whether or not treatment is provided; or

(B) the patient is permanently unconscious; ...."

By specifying the part of the determination that the physicians have to make, subparagraph (i) implicitly leaves it up to the surrogate to make the other part of the determination.

Second, a determination regarding the burden of the treatment to the patient is a subjective determination that does not appear to belong principally to the physician. In fact, the Task Force in When Others Must Choose, made it clear that it is the surrogate who determines "the benefits and burdens of treatment" (p.62). It also emphasized that the concept of "excessive burden" should be understood to reflect the past values, wishes, and preference of the patient (p113), which suggests a surrogate decision.

Nonetheless, the decision about burden warrants participation and input from the physician and a dialogue between the surrogate and the physician about the decision. (Revised September 8, 2010).

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6. Q - Turning to the second standard, who determines whether a treatment would be "inhumane or extraordinarily burdensome"?

A. The clause with the second standard allows the withdrawal or withholding of life-sustaining treatment in the following circumstances:

(ii) 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, as determined by an attending physician with the independent concurrence of another physician to a reasonable degree of medical certainty and in accord with accepted medical standards.

Like the first standard, this second standard requires an assessment of the burden to the patient, and then a clinical determination regarding irreversibility which is clearly assigned to the physician. It therefore seems that the similar structure of subparagraphs (i) and (ii) indicate a similar division of responsibility - the surrogate decides whether the treatment would be "inhumane or extraordinarily burdensome" and the physician determines whether there is an irreversible condition. This interpretation would also be consistent with the Task Force's view of the subjective and non-clinical nature of a burden determination.

Moreover, the statute requires the physician's judgment to be made "to a reasonable degree of medical certainty and in accord with accepted medical standards," standards that are inconsistent with a subjective judgment about the burden of treatment. Finally, the statute requires Ethics Review Committee approval when a general hospital attending physician "objects to a surrogate's decision under" the inhumane/ extraordinary burden standard to withdraw nutrition and hydration.

But as stated previously, the statute is not specific on this point; the statute simply requires that the conditions are satisfied. Also, as stated previously, the decision about burden warrants participation and input from the physician. (Revised September 8, 2010).

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7. Q - What qualifies as an "irreversible or incurable condition"?

A - The statute does not define the phrase, or explain it further, but from the context, purpose and background it is clear that the phrase relates to medical conditions that are severely debilitating as well as irreversible and incurable. As the Task Force wrote in When Others Must Choose (p112):

"Other Cases - Decisions to forego life-sustaining treatment may also be appropriate for some patients who are neither terminally ill nor permanently unconscious. For example, an aggressive and painful course of chemotherapy might extend the life of a patient with a chronic degenerative illness who has irreversibly lost the ability to speak or to recognize people. A surrogate might decide that the chemotherapy would be excessively burdensome to the patient, based on the patient's prior wishes or an assessment of the patient's interests.

"Decisions to forego life-sustaining treatment for patients who are neither terminally ill nor permanently unconscious require heightened scrutiny...."

V. Decisions about life-sustaining treatment for minor patients (§ 2994-e)

1. Q - This section provides that if a minor has decision-making capacity, then a parent's decision to withhold or withdraw life-sustaining treatment may not be implemented without the minor's consent. The former DNR had required the minor's "assent." Is there a difference?

A - No. Under either law, the minor must agree and the decision cannot go forward without the minor's approval if the minor shows an ability to understand and appreciate the treatment decision issues in question.

VI. Health care decisions for adult patients without surrogates. (PHL §2994-g) *(Revised September 21, 2010)*

1. Q - Under the former DNR law, a DNR order could be entered for an incapable patient who did not have a surrogate if the physician and a concurring physician determined that resuscitation would be" medically futile" (i.e., if CPR would "be unsuccessful in restoring cardiac and respiratory function or that the patient will experience repeated arrest in a short time period before death occurs"). Can a physician still do that?

A - The language of the standard has changed, but it still ordinarily support the entry of a DNR order if resuscitation would be "medically futile" as defined above. Under the FHCDA, the physician and a concurring physician would need to determine that (i) attempted resuscitation (in the event of arrest) would offer the patient no medical benefit because the patient will die imminently, even if the treatment is provided; and (ii) the attempt would violate accepted medical standards.

2. Q - With respect to a hospice-eligible patient who is found to lack capacity and who does not have a surrogate, can an attending physician or attending nurse practitioner both enroll the patient into hospice and approve a DNR order for the patient?

A. Yes. A 2015 amendment to the FHCDA set forth a three step process to secure a "decision regarding hospice care" for such patient. The process involves (i) a determination by the attending physician (later amended to include attending nurse practitioner) based on the FHCDA's standards for a surrogate decision; (ii) a concurring opinion by another physician or NP; and (iii) approval; by an ethics review committee. The 2015 bill and bill memo make clear that a "decision regarding hospice care" can include a decision to issue a DNR order or to withdraw or withhold other life-sustaining treatment as part of the hospice plan of care. *(Added December 28, 2018)*

3. Q - For a hospice patient without a surrogate - is the approval of an Ethics Committee required for every change in the plan of care?

A - No. While the bill language could be more clear on this point, the apparent intent was to require Ethics Committee approval only for the initial plan of care or subsequent major medical or withdrawal of life-sustaining treatment decisions - not routine changes such as medication changes or diet changes. *(Added December 28, 2018)*

VII. DNR Orders (PHL § 2994-1)

1. Q - The FHCDA does not include a clause from the prior DNR law that patients who do not have DNR orders are "presumed to consent to the administration of cardiopulmonary resuscitation in the event of cardiac or respiratory arrest." Former PHL § 2962.1. Does that mean there is no longer such a presumption? And does that mean that DNR orders can be written without consent?

A - No and no. The clause in the prior DNR law simply reflected the principle that in an emergency a patient is presumed to consent to necessary treatment, unless there was a prior objection to such treatment. That principle is still supported by statute and case law: patients are still presumed to consent to potentially beneficial CPR in the event of cardiac arrest unless there is a DNR order.

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2. Q - The former DNR law had a provision governing consent to a DNR order by a patient with capacity. Among other things, it set forth witnessing requirements for such consent. There does not seem to be any similar provision in the FHCDA. So what are the current requirements for consent by a capable patient to a DNR order?

A. The FHCDA repealed the former DNR law provision governing consent to a DNR order by an adult patient in a general hospital or nursing home, and did not replace it with a parallel clause in the FHCDA. As a matter of constitutional and common law, it is clear that a patient with capacity can consent to a DNR or DNI order, just as a patient with capacity can direct the withdrawal or withholding of other life-sustaining treatments. Under State health regulations, hospital patients and nursing home residents have a right to refuse medication and treatment after being fully informed and understanding the probable consequences of such actions. Hospitals and nursing homes may document such decisions in the manner they would document any consent by a patient to the withholding of life-sustaining treatment. (Added September 8, 2010).

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3. Q - The FHCDA does not include a clause from the prior DNR law that allowed "therapeutic exception" to the requirement to secure the consent of a patient with capacity. That is, it allowed a DNR order to be issued based on a surrogate's consent rather than the patient's consent when doctors agreed that the discussion about DNR would be harmful to the patient. Was that omitted deliberately? Can a surrogate still consent to a DNR order on behalf of a capable patient?

A - The "therapeutic exception" provision was deliberately omitted from the FHCDA, and a surrogate may no longer make a DNR decision for a patient who has capacity. (Added September 8, 2010).

VIII. Implementation and review of decisions. (PHL § 2994-k) *(Revised September 21, 2010)*

1. Q - Are DNR orders still required to be reviewed by an attending physician in hospitals every 7 days and in nursing homes every 60 days? If not, how often are they required to be reviewed?

A - The DNR law, including its specific timeframes for reviewing the orders, no longer applies to hospitals and nursing homes. Instead, the FHCDA requires facilities to devise their own policies regarding review of such orders, and other life-sustaining treatment decisions. Thus a hospital or nursing home policy could continue to follow the former DNR Law review periods, or alter the review periods, or even require the attending physician to set forth a review period for a patients on a case by case basis. DNR decisions should be treated like every other decision to withhold or withdraw life-sustaining treatment. If regular medical review is medically indicated, then it should be done.

Note that nonhospital DNR orders must be reviewed every 90 days. (See PHL § 2994-dd(4)). This is the same period as was required under the former § 2977(8). (Revised September 8, 2010).

IX. Interinstitutional transfers (PHL §§ 2994-l, 2994-ff)

1. Q - If a patient is admitted to a hospital with a DNR order that was issued in another hospital or nursing home or a nonhospital DNR order, can the attending physician issue an order to continue the DNR order?

A - The order that arrived with the patient remains effective until an attending physician examines the patient. That physician must then continue the order, unless the physician determines that the order is no longer appropriate or authorized. In deciding whether the order is still appropriate, the physician should consider whether the difference in response time to a cardiac arrest in the hospital might mean that the prognosis following CPR for the patient would be different, and whether a discussion with the decision-maker for the non-hospital order is warranted. Before canceling the order, the attending physician must make reasonable efforts to notify the person who made the decision. If such notice cannot reasonably be made prior to canceling the order, the attending physician must make such notice as soon as reasonably possible after cancellation. (Revised September 8, 2010).

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2. Q - When a patient in a hospital with DNR order is transferred to a nursing home, does the nursing home need to get the resident's or surrogate's consent again to re-enter the DNR order? Will the nursing home ever have to get that consent?

A - The FHCDA provides that the attending physician at the nursing home can enter the DNR order without having to get another consent. The nursing home will never have to get that consent, unless the DNR order is revoked or suspended, and the issue is whether to enter it again.

X. Ethics review committees (PHL § 2994-m)

1. Q - Are decision by the Ethics Review Committee (ERC) advisory or binding?

A - Recommendations and advice of the ERC are advisory and nonbinding, except in three limited circumstances:

(i) In a nursing home, ERC approval is required before a surrogate will have the authority to refuse life-sustaining treatment under the standard that applies to residents who are not terminally ill or permanently unconscious (but this is not applicable to DNR decisions);

(ii) In a general hospital, if the attending physician objects to a surrogate's decision to withdraw or withhold artificial nutrition and hydration based on the standard that applies to patients who are not terminally ill or permanently unconscious, the decision cannot be implemented until the ERC determines that the decision meets surrogate decision-making standards; and

(iii) A decision by an emancipated minor (without the consent of a parent or guardian) to have life-sustaining treatment withdrawn or withheld must be approved by the ERC.

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2. Q - Is it mandatory or recommended in the Act for at least for one committee member to be a person from the community (a person that has no obligation to the facility)?

A - It is mandatory.

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3. Q - Our hospital has a large ethics committee that now mostly does retrospective case review and policy review. Should that be the FHCDA ethics review committee?

A - Not necessarily. The FHCDA ethics review committee needs to be lean enough to respond to cases in real time. It might be preferable to designate a 5 -7 person body for that purpose.

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4. Q - Who appoints and removes the members of the committee?

A - The hospital or nursing home can decide this, and should set it forth in its policy.

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5. Q - Are there quorum requirements? Voting rules?

A - The hospital or nursing home can decide these matters, and should set its rules in its policy.

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6. Q - What does the FHCDA mean by requiring that the committee "must include at least five members who have demonstrated an interest in or commitment to patient's rights or to the medical, public health, or social needs of those who are ill."? Does it require five members in addition to other members who meet the other qualifications?

A - The FHCDA does not require five members with a "demonstrated interest" in addition to other members who meet other qualifications. The law requires that a doctor and nurse serve on the committee and they would certainly meet the "demonstrated interest" test. Rather, the clause should be read to mean (1) that the committee must have at least five members, AND (2) those five members should have some background in the issues the committee will face (e.g., they should be health care professionals, health care advocates, persons with significant experiences as patients or patient's family members, and other persons with a demonstrated interest or involvement in the issues.) A committee may also have members who have no record of involvement in the interests of patients. But at least five members should have that record.

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7. Q - Does the ERC displace the role of an existing ethics consultation service? Or for that matter, of the attending physician, social worker or chaplain in attempting to resolve disputes?

A - No. The FHCDA expressly recognizes that facilities may first use less formal means to attempt to resolve disputes. Those other means may include already existing ethics subcommittees and ethics consultation services. The FHCDA expressly recognizes that facilities may use less formal means first to resolve disputes. However, if a person connected with the case requests a review by the ERC, it must be provided regardless of whether less formal means have yet been exhausted So the committee should not be regarded as an alternative to arranging a meeting between the care team and the family, or seeking an ethics consultation. So the committee should not be regarded as an alternative to arranging a meeting between the care team and the family, or seeking an ethics consultation. (Revised September 8, 2010).

XI. Rights to be publicized. (PHL §2994-u)

1. Q - The FHCDA requires hospitals and nursing homes to distribute to patients and residents a statement of their rights under the FHCDA. Where can one find that statement?

A - - Hospitals should distribute the revised version of DOH publication 1449, "Your Rights as a Hospital Patient in New York State," which includes the section "Deciding About Health Care: A Guide for Patients and Families." Nursing Homes should distribute DOH publication 1503, "Deciding About Health Care: A Guide for Patients and Families." Both are available on the DOH website, as well as on this NYSBA Information Center website.

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2. Q - Do hospitals and nursing homes have to provide the PHL § 2994-u statement to current inpatients/residents?

A - "DOH has taken the position that hospitals did not have to provide the statement to already-admitted inpatients on June 1, 2010, but nursing homes do have to provide the statement to all of their nursing home residents, even those who were admitted before June 1, 2010. (Added September 8, 2010)."

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3. Q - Does the statement need to be provided to the patient or resident if the patient or resident lacks decision-making capacity?

A - No, in that case the statement should not be provided to the patient or resident; it should be provided to whoever has authority to make health care decisions for the patient or resident. *(Added September 8, 2010).*

XII. Nonhospital DNR orders

1. Q - Why did Chapter 8 create a new Article 29-CCC relating to Nonhospital DNR orders?

A - Previously, nonhospital DNR orders were governed by a section of PHL Article 29-B - Orders Not to Resuscitate. But Article 29-B was amended to make it apply only in mental hygiene facilities. As a result, there was a need to create a new place to preserve the law on nonhospital DNR orders.

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2. Q - Does the new provision on nonhospital DNR orders differ much from the prior nonhospital DNR provision?

A - The main difference is that surrogate consent is now governed by the standards in the FHCDA, not those in the former DNR law. Also, the prior law directed only emergency medical service personnel and hospital emergency services personnel to honor nonhospital DNR orders. The new provision also directs hospice and home care services agency personnel to honor such orders.

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3. Q - The new non-hospital DNR provision states that consent by a surrogate for a patient in a mental hygiene facility is now governed by PHL Article 29-B - Orders Not to Resuscitate in Mental Hygiene Facilities. But what if the patient is eligible for a family member to make the decision under SCPA §1750-b?

A - OPWDDOPWDD has taken the position that the family member would make the decision under the standard set forth in SCPA §1750-b, and not the standard PHL Article 29-B.

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4. Q - Can a FHCDA surrogate consent to a nonhospital DNR order?

A - Yes.

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5. Q - Can a FHCDA surrogate consent to a nonhospital DNI order using MOLST?

A - PHL Article 29 CCC is ambiguous on this point, but DOH's answer to this question is yes. Non-hospital DNR orders can also be issued on the standard form available on the DOH website.

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6. Q - Can a FHCDA surrogate consent to other nonhospital medical orders (medical orders other than DNR/DNI) under Article 29 CCC?

A - No, but the surrogate and others may have clear and convincing evidence of the patient's wishes. And that evidence may be documented, including on a MOLST form.

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7. Q - Under the former PHL § 2977(4), the parent or legal guardian of a minor could consent to a nonhospital DNR order for the minor, but under PHL § 2994-cc, there is no provision for consent by the parent or legal guardian or a minor. Can a parent or legal guardian of a minor still consent to a nonhospital DNR order (or a nonhospital DNI order using the MOLST form)?

A - Yes, in enacting Laws of 2010, chapter 8, there was no intent to take away the ability of the parent or legal guardian of a minor to consent to a nonhospital DNR order for the minor. A DNR or DNI order is a medical order signed by a physician, and the parent or legal guardian of a minor can consent to a medical order to provide comfort measures only (palliative care) for the minor under PHL § 2504(2). When a DNR order is signed by a physician, that is not a case where the minor is receiving no medical treatment (see, Matter of Hofbauer, 47 NY2d 648). The parent or legal guardian of a minor can consent to nonhospital DNR or DNI orders in the same manner that they would consent to them under FHCDA. (Revised September 8, 2010).

XIII. Orders not to resuscitate for residents of mental hygiene facilities (Chapter 8, §22)

1. Q - Why did Chapter 8 amend the former DNR Law (PHL Article 29-B) to make it apply only to mental hygiene facilities?

A - Because the new FHCDA now governs DNR orders in hospitals and nursing homes, but there was a need to continue the applicability of the former DNR law to mental hygiene facilities.

XIV. Health Care Proxy Law (Chapter 8, §§23-24)

1. Q - Did Chapter 8 amend NY's Health Care Proxy Law? How?

A - Yes. Chapter 8 amended NY's Health Care Proxy Law in three ways. First it added a provision to protect institutional and provider conscience rights with respect to health care agent decisions to the same extent that the FHCDA recognizes such rights with respect to surrogate decisions. Second, it added a clause, similar to one in the FHCDA, that basically states that if an agent directs the provision of life-sustaining treatment, a hospital or provider that does not wish to provide such treatment must nonetheless comply with the agent's decision pending either transfer of the patient to a willing hospital or individual provider, or judicial review. Finally, the definition of life-sustaining treatment is amended to conform to the FHCDA definition.

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2. Q - Can a health care agent now make decisions regarding artificial nutrition and hydration even if the patient's wishes are not reasonably known?

A - No, the health care proxy law still provides that the agent can only authorize the withdrawal of artificial nutrition and hydration based on the patient's wishes, if reasonably known, and not on the patient's best wishes if the patient's wishes are not reasonably known. This restriction is hard to reconcile with the FHCDA, which allows a surrogate to must make decisions on any treatment, including artificial nutrition and hydration, based on the patient's wishes if reasonably known, or else the patient's best interests. However, in many instances a health care agent may be able to act as the surrogate for purposes of decisions regarding artificial nutrition and hydration. In the future, the Legislature should amend the Health Care Proxy Law to eliminate the disparity.

Meanwhile, it is useful to note that a health care agent does not need "clear and convincing evidence" of the patient's wishes to authorize the withdrawal of artificial nutrition and hydration; nor does the law require that the patient's wishes be in writing. The patient's wishes only need to be "reasonably known."

XV. MHL Article 81 Guardianship Law (Chapter 8, §§23-24)

1. Q - Did Chapter 8 amend NY's MHL Article 81 Guardianship Law? How?

A - Yes. Chapter 8 amended the Guardianship Law to authorize an MHL Article 81 guardian of the person to act as a surrogate under the FHCDA for decisions in hospitals. It also repeals a provision in MHL Article 81 that restricted the authority of a guardian to make life-sustaining treatment decisions.

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2. Q - Do existing MHL Art 81 guardians automatically gain the authority of FHCDA surrogates, or does a court have to give them that authority?

A. - An MHL Art. 81 guardian who had been given authority to make medical treatment decisions for the incapacitated person should now be regarded as having the authority of a surrogate. A guardian who was not given such authority would not be considered a surrogate (unless the guardian qualifies as a surrogate under another basis). (Added September 8, 2010.)

XVI. SCPA §1750-b Guardianship (The Health Care Decisions Act for Intellectually Disabled Persons) (Chapter 8, §§23-24)

1. Q - How did Chapter 8 amend the Health Care Decisions Act for Mentally Retarded (now Intellectually Disabled) Persons (SCPA §1750-b?)

A - CHAPTER 8 AMENDED SCPA §1750-B TO INSERT A DEFINITION OF "LIFE-SUSTAINING TREATMENT" IT ALSO AMENDED §1750-B TO ALLOW THE WILLOWBROOK CONSUMER ADVISORY BOARD TO ACT AS THE HCDA GUARDIAN FOR CLASS MEMBERS.

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