



SUFFOLK ACADEMY OF LAW
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PATIENT WISHES OR BEST PRACTICES?
Clinical, Ethical and Legal End of Life Issues in a Hospital Setting

FACULTY

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Program Coordinators: SCBA Elder Law & Health & Hospital Law Committees

November 9, 2022
Suffolk County Bar Association, New York

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**PATIENT WISHES OR BEST PRACTICES?
Clinical, Ethical and Legal End of Life Issues in a Hospital Setting
November 9, 2022
5:00 p.m. – 7:15 p.m.
Virtual Webinar**

- 5:00 - 5:05 p.m.** **Welcome and Introductions: Evelyn Lin**
- 5:05 – 5:35 p.m.** **Advance Directives and Legal Authority– Cindy Raskin Rocco – 30 minutes**
- Health Care Proxy v Living Will and Medical Orders for Life-Sustaining Treatment (MOLST)
 - Guardian medical decision making under Article 17A and Article 81
 - Surrogate decision making under the Family Health Care Decisions Act (FHCA)
- 5:35 – 6:05 p.m.** **Medical Ethics vs. Legal Ethics – Edward McArdle – 30 minutes**
- Four ethical principles of health care decision making and the hospital ethics consultation
- 6:05– 6:35 p.m.** **Common Types of Difficult Medical Treatment Disputes – Dr. Grace LaTorre – 30 minutes**
- Role of palliative care and the interface with health law including legal issues that come up related to end of life care and how they can impact patient care.
- 6:35 – 7:05 p.m.** **Panel Discussion – Edward McArdle, Dr. Grace LaTorre – 30 minutes**
- Discussion of difficult consultations with tips for attorneys on how to make health care proxies and living wills more effective.
 - Dispute Resolution process
- 7:05 – 7:15 p.m.** **Panel and Q & A – 10 minutes**



Cindy Raskin Rocco, Esq. – Raskin Rocco Law PLLC

Cindy Raskin Rocco is the principal attorney at Raskin Rocco Law PLLC. She is a member of the New York State, Nassau County and Suffolk County Bar Associations and the Nassau County Estate Planning Council. She was appointed to the Suffolk County District Administrative Judge's Task Force on Mental Hygiene Law Article 81 and to the Mediation Panel of the Suffolk County Surrogate's Court. She has served as a Part 36 appointee as Court Evaluator, Counsel for Alleged Incapacitated Persons, and Supplemental Needs Trustee, as well as Court appointed Guardian ad Litem in Nassau and Suffolk County Surrogate's Court proceedings. From 2020-2022 she served as co-chair of the Suffolk County Elder Law & Estate Planning Committee.

Prior to attending law school, Cindy graduated from SUNY Stony Brook with a BS degree in Cardiopulmonary Sciences. She is a Registered Respiratory Therapist and worked in numerous hospitals in NYC and on LI before taking a position as Assistant Professor and Director of the BS degree program in Respiratory Therapy at Long Island University – Brooklyn Campus.



PROFESSOR EDWARD MCARDLE

Edward McArdle is a clinical assistant professor and ethics consultant at SUNY Upstate Medical University and an adjunct professor at Cornell Law School. Before that, he was an attorney at the New York Attorney General's Office who represented the State in many litigated health care matters.

Professor McArdle's primary interests are teaching and researching ethical dilemmas at the intersection of law, medicine and bioethics and figuring out how to resolve them.



Grace N. LaTorre DO, MS – Director of Palliative Care at Stony Brook University Hospital

Grace N. LaTorre DO, MS, is a Hospice and Palliative Medicine board-certified physician and educator. Dr. LaTorre is the Director of Palliative Care at Stony Brook University Hospital, the largest academic center in Long Island, New York. Furthermore, she is the Director of Palliative Care Education and Program Director of the Hospice and Palliative Medicine Fellowship. In her role she is responsible for overseeing a large interdisciplinary team and developing palliative care curricula throughout Stony Brook Medicine. One of her strongest contributions to palliative care education at Stony Brook Medicine has been to integrate “hands on training” via the simulation lab for medical students and resident trainees of various disciplines.

Grace was also responsible for leading the *Early Palliative Care Response* during the COVID-19 pandemic at Stony Brook University Hospital. Dr. LaTorre along with her team cared for and supported hundreds of patients and their respective families during this time. Grace’s interest expands beyond education, and include research related to the impact of palliative care interventions in the oncology patient population as well as end of life care for vulnerable patients. Grace graduated from NYIT College of Osteopathic Medicine in Old Westbury, Long Island, and completed her Internal Medicine training and Hospice and Palliative Medicine Fellowship at Hofstra North Shore-LIJ Health System.

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LEGAL AUTHORITY FOR MEDICAL DECISION-MAKING:

Health Care Proxy, Living Will, Family Health Care Decisions Act (FHCDA) and Medical Orders for Life Sustaining Treatment (MOLST)

- I. Health Care Proxy** -enables competent adults to protect their health care wishes by appointing someone they trust - a health care agent - to decide about treatment on their behalf when they are unable to decide for themselves. Unless stated otherwise, a health care agent can make all decisions that the patient could make while competent (NY law prohibits active euthanasia and assisted suicide). The proxy law is based on recommendations by the NYS Task Force on Life and the Law, established by Mario Cuomo in the 1980's in response to dissatisfaction in NY with decisions by the Court of Appeals with respect to withholding or withdrawing life-sustaining treatment from dying patients. The Task Force recommendations became law in 1992.
- A. Article 29-C of the PHL is the NY statute governing health care agents and proxies
1. Who may appoint? A competent adult may appoint an agent in accordance with the terms of the article, delegating authority to make health care decisions.
 - a. §2981 Presumption of Competence: Every adult is presumed competent to appoint an agent, unless adjudged incompetent **or** otherwise adjudged not competent to appoint a health care agent, **or** a committee or guardian of the person has been appointed for the adult pursuant to Article 78 of the MHL or Article 17-A of the SCPA.
 - b. §2980 (3) Capacity to make health care decisions means the “ability to understand and appreciate the nature and consequences of health care decisions, including the benefits and risks of and alternatives to proposed health care, and to reach an informed decision.”
 2. §2981 (2) Execution of health care proxy
 - a. §2981 (2) (a) Must be signed and dated by the adult in the presence of two adult witnesses who shall also sign the proxy.
 - b. §2981 (2) (a) Another person may sign and date the health care proxy for the adult if the adult is unable to do so, at the adult’s direction and in the adult’s presence and in the presence of two adult witnesses who also shall sign.

- c. The two witnesses shall state that the principal executed the proxy willingly and free from duress.
 - d. **A person appointed as health care proxy may not be a witness.**
 - e. §2981 (2) (b) Persons residing in a mental hygiene facility operated by the office of mental health: at least one witness shall be an individual not affiliated with the facility.
 - f. §2981 (2) (c) Persons residing in a mental hygiene facility operated or licensed by the office for people with developmental disabilities: at least one witness shall be an individual who is not affiliated with the facility and at least one witness shall be a physician, nurse practitioner, physician assistant or clinical psychologist
3. §2981 (4) Commencement of agent’s authority: upon determination that the principal lacks capacity to make health care decisions pursuant to §2983.
4. §2981 (5) Contents and form of health care proxy
- a. Identify the principal and agent, and possibly alternate agent. Each person can appoint only one agent at a time.
 - b. Indicate that the principal intends the agent to have authority to make health care decisions
 - c. May include the principal’s wishes, and limitations on the agent’s authority
 - d. May provide an expiration date.
 - e. Must not be incorporated into POA.
 - f. §2981 (6) Alternate agent may serve when it is determined that agent is not reasonably available, willing or competent to serve as agent.
 - g. Reverts back to agent if/when they become available.
5. §2982 (1) Scope of authority: any and all health care decisions subject to any express limitations on the health care proxy
6. **§2982 (2) Decision making standard:** After consultation with health care professionals, the agent shall make health care decisions
- a. In accordance with the principal’s wishes, religious and moral beliefs; or
 - b. If not reasonably known and cannot be reasonably be ascertained, in accordance with the principal’s best interests
 - c. **Exception:** if principal’s wishes regarding artificial nutrition and hydration are not reasonably known or cannot be ascertained, the agent shall not have the authority to make these decisions.
7. **§2983 Determination of lack of capacity:**
- a. By attending practitioner to a “reasonable degree of medical certainty.” Determination shall be made in writing, include practitioner’s opinion regarding cause and nature of incapacity as well as extent and probable duration. Shall be included in patient’s

- medical record.
- b. For decisions regarding withdrawing or withholding artificial nutrition and hydration, practitioner must consult with another practitioner to confirm such determination of lack of capacity and include the determination in the patient's chart.
 - c. For decisions in connection with a lack of capacity in patients due to mental illness, the practitioner must be or consult with a psychiatrist.
 - d. For decisions in connection with a lack of capacity in patients due to developmental disability, the practitioner must be or consult with a physician, NP, PA or clinical psychologist who has been employed for a minimum of two years in a facility for people with developmental disabilities.
 - e. An MD, PA or NP who is agent shall not make the determination.
 - f. An agent may request a determination from attending practitioner regarding the principal's lack of capacity to make health care decisions. This is not to be construed as an incapacity for any other purpose.
 - g. If the principal objects to the determination of incapacity or to a decision made by an agent, the principal's objection or decision shall prevail unless principal is adjudicated to lack capacity to make health care decisions.
 - h. A principal may recover capacity, and the authority of the agent shall cease.
8. §2984. Provider's obligations
- a. Insert health care proxy in principal's records
 - b. Comply with decisions of agent, subject to limitations in the health care proxy and pursuant to provisions regarding determining lack of capacity.
 - c. May not honor decisions if contrary to formal policy of the hospital based on religious beliefs, provided
 - (1) the hospital informed the patient or the agent of such policy prior to or upon admission, and
 - (2) patient is transferred to another hospital which is willing to honor decision.
 - d. An individual health care provider may not honor decisions if contrary to individual's religious beliefs. In that case the hospital must transfer responsibility for patient to another health care provider.
 - e. §2984 (5) If agent directs provision of life-sustaining treatment, the denial of which is reasonably likely to result in death, a hospital or individual provider that does not wish to provide such treatment shall comply, pending either transfer to a willing hospital or

- another provider, or judicial review. §2992.
9. §2985. Revocation
 - a. Competent adult may revoke by notifying the agent or provider, orally or in writing. Must evidence specific intent to revoke.
 - b. Upon execution by the principal of a subsequent health care proxy.
 - c. Appointment of spouse as agent is revoked upon divorce or legal separation, unless otherwise specified.
 - d. If proxy is revoked, practitioner has duty to record revocation in patient's medical record and notify the agent and other medical staff.
 10. §2986. Immunity
 - a. Provider immunity. No criminal or civil liability, or deemed to have engaged in unprofessional conduct, for honoring a good faith decision by an agent.
 - b. Agent Immunity. No criminal or civil liability for a decision made in good faith by an agent.
 11. §2990. Proxies executed in other states. Considered validly executed if executed in compliance with the law of that state.
 12. **§2992. Special proceeding authorized**
 - a. Authorizes certain identifiable individuals to commence a proceeding with respect to any dispute arising under this article.
 - (1) health care provider
 - (2) guardian
 - (3) members of the principal's family
 - (4) a close friend of the principal
 - (5) commissioner of health, mental health or developmental disabilities
 - b. Proceeding to:
 - (1) determine the validity of the health care proxy
 - (2) have the agent removed if (a) not reasonably available, (b) acting in bad faith, or (c) is the subject of an order of protection or has been arrested or charged for an act that caused the principal's lack of capacity
 - (3) override the agent's decision on the grounds that (a) the decision was made in bad faith or (b) the decision is not in accordance with the standards in §2982 (1) or (2)
 13. A copy of a health care proxy is as good as an original.

II. Living Wills

- A. An expression of values and goals at a time when a patient remains able to express them. Distinguish: the health care proxy authorizes the agent to decide about treatment and the living will provides guidance to the agent about the patient's health care wishes.

- B. Purpose
 - 1. To increase respect for patients' wishes by promoting the treatment they say they want if they lose decision-making capacity
 - 2. Protect the patient's family from having to make difficult decisions on behalf of the patient
 - 3. Reduce futile interventions that lead to suffering of the patient and wasted health care resources
- C. Possible risk and harm
 - 1. Inadequate patient understanding.
 - 2. Ambiguity of terms leading to imposition of the values of the decision-maker, ie. Subtleties of defining terminal, incurable, irreversible illness and reasonable hope for recovery. Studies have shown that there is significant variability among physicians' definition of a terminal condition.
 - 3. Early withdrawal of interventions due to misinterpretation of living will.
 - 4. Mutability of treatment preferences.

III. Family Health Care Decisions Act - also came out of the recommendations of the NYS Task Force in a later report supporting legislation for appointment of surrogate decision makers. This led to the passage in 2010 of the Family Health Care Decisions Act for those who have failed to appoint their own health care agents.

- A. Article 29-CC of the PHL is the NY Statute governing surrogate decision-making
 - 1. §2994-b. Priority of other surrogate decision making laws
 - a. Applies to decisions provided in a hospital or hospice care, for a patient who lacks decision making capacity.
 - b. Practitioner shall make reasonable efforts to determine if health care agent has been appointed.
 - c. If practitioner believes that the patient has a history of ID or DD, has received services for ID or DD, or patient has been transferred from a mental hygiene facility, then practitioner must make reasonable efforts to determine
 - (1) whether the patient has an appointed 17-A guardian. If so, Article 1750-b of the SCPA governs, and the guardian has the authority to make any and all health care decisions on behalf of the person who is ID that such person could make if such person had capacity, including decisions to withhold or withdraw life-sustaining treatment.
 - (2) If no guardian appointed but principal falls within the class of persons described in SCPA 1750-b (a), decisions to withdraw or withhold life sustaining treatment are controlled by SCPA 1750-b. A qualified family member may be the decision maker if have a significant and

ongoing involvement in the person's life so as to know their needs and reasonably ascertain the persons wishes, including moral and religious beliefs.

2. §2994-c. Determination of Incapacity
 - a. Presumption of capacity. Every adult shall be presumed to have capacity, unless determined otherwise pursuant to a court order
 - b. Initial determination. Practitioner will make a determination of lack of decision making capacity to *a reasonable degree of medical certainty* subject to a concurring determination independently made
 - (1) if a determination is made of lack of decision making due to mental illness, the physician must have credentials in psychiatry or neurology
 - (2) if a determination is made of lack of decision making due to developmental disability, the professional must have qualifications in this area.
 - (3) if the consult for a concurring determination disagrees with the attending practitioner's determination, the matter shall be referred to the *ethics review committee* if it cannot otherwise be resolved.
 - c. Notice of the determination of decision making incapacity shall be immediately given to the patient, and to at least one person on the surrogate list highest in order of priority.
 - d. This determination of incapacity shall not be construed to mean the patient lacks capacity for any other purpose.
 - e. If the patient objects to the determination, or to the choice of surrogate, the patient shall prevail unless adjudicated unable to make a decision or incompetent.
3. §2994-d. Identifying the surrogate
 - (1) Guardian authorized to decide health care pursuant to Article 81 of MHL
 - (2) Spouse, if not legally separated, or the domestic partner
 - (3) Son or daughter 18 or older
 - (4) Parent
 - (5) Brother or sister 18 or older
 - (6) Close friend
 - b. Scope of authority. Any and all health care decisions the patient could make
 - c. Commencement of Authority. Upon determination of lack of decision-making capacity and identification of a surrogate. Authority ceases when decision making capacity returns.
 - d. Right to be informed. The Surrogate shall have the right to receive medical information necessary to make informed decisions.
 - e. Decision making standards.

- (1) In accordance with patient's wishes, including religious and moral beliefs; or
 - (2) If wishes not reasonably known and cannot be ascertained, in accordance with the patient's best interests.
 - (3) To withhold or withdraw life-sustaining treatment. May be done orally or in writing. Authorized only if:
 - (a) Treatment is burdensome to the patient and the patient is not expected to survive 6 months or the patient is permanently unconscious or treatment would involve pain and suffering as to be deemed inhumane and patient in an irreversible or incurable condition.
4. §2994-e. Minor patients
- a. Authority of parent or guardian to make decisions about life sustaining treatment.
 - b. Standards
 - (1) in accordance with minor's best interests
 - (2) If the minor has decision making capacity, parent may not withhold treatment without minor's consent
 - c. Emancipated minor
 - (1) minor with decision making capacity may make decision.
5. §2994-f. Obligations of attending practitioner
- a. With respect to a decision to withdraw or withhold life-sustaining treatment made in accordance with this article, the attending practitioner shall record the decision in the patient's medical record, review the basis for the decision and shall either implement the decision or object to the decision, make his/her reasons known to the decision-maker and either transfer the patient's care to another or refer the matter to the *ethics review committee*.
 - b. If the attending has actual notice of the following objections or disagreement, he/she shall refer the matter to the *ethics review committee*:
 - (1) a health care or social services practitioner consulted for determination of lack of capacity disagrees; or
 - (2) anyone on the surrogate list objects to the designation of the surrogate; or
 - (3) anyone on the surrogate list objects to the surrogate's decision; or
 - (4) parent/guardian objects to the decision of another parent/guardian; or
 - (5) a minor patient refuses life sustaining treatment, parent/guardian wishes the treatment to be provided; or the minor objects to an attending practitioner's determination

- about decision making capacity or recommendation about life-sustaining treatment.
- c. If a surrogate directs life sustaining treatment, the denial of which in reasonable medical judgment would likely result in death, a hospital that does not wish to provide such treatment shall comply pending transfer or judicial review in accordance with §2994-r.
6. §2994-g. Patients without surrogates. For an adult who has been determined to lack medical decision making capacity:
- a. If none can be identified, the hospital shall identify to the extent possible the patient’s wishes and preferences, including religious and moral beliefs, and record findings in medical record.
 - b. Decision making standards shall not be based on financial interests of the hospital,
 - (1) An attending practitioner is authorized to decide about routine medical treatment.
 - (2) Major medical treatment. An attending shall make a recommendation in consultation with hospital staff responsible for patient’s care. At least one other health practitioner must independently determine concurrence.
 - (3) Decisions to withhold or withdraw life sustaining treatment.
 - (a) Court of competent jurisdiction may make decision; or
 - (b) Attending physician, with concurrence of a second medical practitioner, determines that life sustaining treatment offers no medical benefit **and** the provision of life sustaining treatment would violate accepted medical standards. Does not apply to treatment to alleviate pain or discomfort.
 - (4) Decisions regarding hospice.
 - (a) Attending practitioner in consultation with staff responsible for care.
 - (b) There is a concurring opinion; and
 - (c) ***Ethics review committee of facility must review the decision***
 - c. Medical practitioner objection - ***matter shall be referred to the ethics review committee*** if it cannot be resolved.
7. §2994-i. Policies for orders not to resuscitate. Shall be written in the patient’s medical record. **Consent to order not to resuscitate is not consent to withhold or withdraw treatment other than CPR.**
8. §2994-j. Revocation of consent.
- a. A patient, surrogate, parent or guardian of a minor may revoke consent to withhold or withdraw at any time, by informing a

- member of the medical or nursing staff.
 - b. Medical practitioner shall immediately record the revocation in medical record, cancel any orders implementing the decision, and notify the staff responsible for care of the revocation.
- 9. §2994-k. Implementation and review of decisions
 - (1) Hospitals shall adopt written policies requiring implementation and regular review of decisions to withhold or withdrawal
- 10. §2994-l. Inter-institutional transfers. For patients with orders to withhold or withdraw life sustaining treatment, any such order shall remain effective until a practitioner examines the transferred patient. Practitioner may issue orders to continue or cancel such order,
- 11. §2994-m. ***Ethics review committee.*** Establishment of committee, written policies, function, committee membership, procedures for ethics review to be discussed by the other presenters.
- 12. §2994-n. Conscience objections. Must a private hospital or an individual health care provider honor a health care decision made pursuant to this article? No, if decision is contrary to a formally adopted hospital policy based on religious beliefs or moral convictions, and the hospital informed the patient of such policies and the patient is transferred promptly to a facility willing to honor the decision.
- 13. §2994-o. Immunity
 - a. Ethics review committee and providers: no criminal or civil liability or charge of unprofessional conduct for acts reasonably and in good faith pursuant to this article
 - b. Surrogates and guardians: no criminal or civil liability for acts reasonably and in good faith pursuant to this article.

IV. Medical Orders for Life Sustaining Treatment (MOLST)

- A. Intended for patients with serious health conditions who
 - 1. want to avoid or receive any or all life-sustaining treatment;
 - 2. reside in a long-term care facility or require long-term care services; and/or
 - 3. might die within the next year.
- B. **A set of medical orders** that reflects treatment the patient wishes to receive today and must be honored by all health care professionals in all settings. Distinguished from a living will in that they are medical documents that are operative upon completion.
- C. Voluntary, and should be offered to patients who are appropriate:
 - 1. Patients whose MD, NP or PA would not be surprised if they die in the next year
 - 2. Patients who live in a NH or receive LTC at home or assisted living
 - 3. Patients who want to avoid or receive any or all life sustaining treatment today.

4. Patients who have one or more advanced chronic conditions, or a new Dx with a poor prognosis.
 5. Patients who have had two or more unplanned hospital admissions in the last 12 months, coupled with increasing frailty, decreasing functionality, progressive weight loss.
- D. Who is not appropriate?
1. Healthy people
 2. Patients who have chronic condition or multiple chronic conditions, but have a long life expectancy
 3. Patients receiving post acute care in a SNF may not be appropriate
- E. Documents a patient's treatment preferences concerning life-sustaining treatment. Authorized in NYS to document nonhospital DNR and DNI orders.
1. Patient's wishes may be expressed by their health care agent or a surrogate.
 2. MD, NP or PA must always
 - a. Confer with the patient or their agent about the patient's Dx, prognosis, goals for care, treatment preferences, and receive consent from the appropriate decision-maker, and
 - b. Sign the orders derived from that discussion.
 - c. In addition to the MOLST form itself, here are legal requirements checklists intended to assist providers in satisfying the legal requirements associated with decisions concerning life-sustaining treatment for patients.
 - d. The MOLST form should be printed on bright "pulsar" pink paper.
 3. May be used in
 - a. hospitals, hospice and nursing homes
 - b. May be used in the community to issue nonhospital DNR and DNI orders.
 4. Signed MOLST form should be transported with patients as they travel to different health care settings.
 5. Orders should be reviewed and may be revised by MD, NP or PA when the patient transitions to different settings or when the patient's preferences and/or medical conditions change.
- F. Represents "clear and convincing evidence" of patient's preferences.
1. If the patient loses capacity, the decisions must be made based on the patient's values, beliefs and goals for care.
 2. If the patient loses the ability to make MOLST decisions and the patient has already made decisions to withhold certain life sustaining treatment, the HCP or surrogate cannot undo the patient's decision.
 3. If the patient loses the ability to make MOLST decisions and the patient has requested full treatment, the HCP or surrogate can make a decision to withhold and/or withdraw other life-sustaining treatment on the MOLST for which the patient requested full treatment, as full treatment represents the standard of care.

- G. Patients with ID or DD and lack capacity to decide:
 - 1. MD must follow special procedures and attach a completed OPWDD checklist before signing the MOLST
 - 2. For those individuals with ID or DD who do not have capacity and do not have a health care proxy, must follow SCPA 1750-b

V. SCPA 1750-b

- A. Scope of authority of guardian
 - 1. Any and all health care decisions that such person could make for themselves.
 - 2. If no guardian appointed, “guardian” also means family member, who have a significant and ongoing involvement in a person’s life so as to have sufficient knowledge of their needs and, if reasonably known or ascertainable, the person’s wishes including religious and moral beliefs.
- B. Decision making standard
 - 1. Best interests of the person and, when reasonably known or ascertainable, based on the person’s religious and moral beliefs.
- C. Life-sustaining treatment
 - 1. Guardian has affirmative obligation to advocate for full provision of health care. If guardian decides to withdraw or withhold life sustaining treatment, then:
 - a. MD must confirm to a reasonable degree of medical certainty that the person lacks capacity to make health care decisions, and place confirmation in medical record. Must consult with another physician to confirm lack of capacity
 - b. MD must note in chart that medical condition is terminal, or permanent unconsciousness or is irreversible and life sustaining treatment would impose an extraordinary burden on such person.

I. ETHICS CONSULTANTS, ETHICS COMMITTEES AND THE MYSTERIOUS WORLD OF HOSPITAL DISPUTE RESOLUTION OF END-OF-LIFE MEDICAL TREATMENT DISPUTES IN NEW YORK: WHAT EVERY LAWYER NEEDS TO KNOW.

Abstract: All hospitals in New York are required to have an internal dispute resolution process for resolution of patient medical treatment disputes, with the most difficult disputes being over whether to withdraw or withheld life-sustaining treatment from a patient who lacks decision-making capacity. Across the country, this function is served in most hospitals by ethics consultants, who provide nonbinding patient-centered ethical guidance to patients, their families and clinicians to assist them in reaching principled resolution of treatment disputes that avoid litigation. Since the passage of the Family Health Care Decisions Act in 2010, New York also has a requirement that hospitals have an ethics review committee available as a forum for hearing of treatment disagreements. These hospital dispute resolution processes are little known outside of hospitals but important for attorneys who provide elder estate planning services in New York to know when preparing advance directives and providing advice to hospitalized clients when issues arise.

INTRODUCTION.

Death is unavoidable. For all of us. We don't get out of this world alive. We all know this. In fact, a big part of what elder law attorneys do is help clients and their families prepare for this inevitability as well as for illness, infirmity and incapacity that often comes first. Powers of attorney, wills, trusts, living wills, and health care proxies, the staples of elder law practice, all serve to prepare clients and their families for what comes next for all of us.

Another likelihood for most of us and for clients is hospitalization. Sickness, old age and death go hand in hand. For attorneys who work with senior clients, it is rare that one will occur

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without one or both of the others.¹ Statistically speaking, there is a about a 60% chance that we will die in a hospital or long-term care facility.²

Another important factor is that hospitalized patients will often lack decision-making capacity either due to the illness leading to the hospitalization or due to pre-existing cognitive decline that is not uncommon as we age. One study found that 67% of terminally ill patients lack decision-making capacity in the last week of their life.³

If you are an experienced attorney, you probably have been asked for advice when a client has been hospitalized. Perhaps some of these calls were about medical treatment disputes and future medical treatment decisions. For instance, questions often arise in ethics consults about the powers of an agent under a Health Care Proxy or applying the language of a Living Will to the circumstances of the patient's current medical condition. Medical treatment disputes can be particularly difficult to resolve, especially when trying to discern the wishes of a patient who now lacks decision-making capacity about the use of life-sustaining treatment.

Hospitals are worlds unto themselves with rules and processes that appear both arbitrary and opaque and make it difficult to provide counsel to hospitalized clients. I am in a unique position because I have seen these issues both as an attorney and as an ethics consultant in an acute care hospital. When I worked as an attorney, I drafted advance directives for patients and litigated many medical treatment disputes over the years. Now, as an ethics consultant, I have a very different perspective on the benefits and drawbacks of advance

¹ Taxes, too, which attorneys also help their clients with, but that's another story.

² CDC Morbidity and Mortality Weekly Report, Quickstats: Percentage of Deaths by Place of Death – National Vital Statistics System, 2000 – 2018 (35.1 % in hospitals and 26.8% in long-term care facilities in 2018, at <https://www.cdc.gov/mmwr/volumes/69/wr/mm6919a4.htm> ; see also Cross SH and Warraich HJ, "Changes in the Place of Death in the United States, NEJM, Correspondence 2019; 381:2369-2370 (similar statistics and notes that the trend for deaths in hospitals and nursing facilities is down and up for hospice).

³ Kolva, E, Rosenfeld, B and Saracino, R. Assessing the Decision Making Capacity of Terminally Ill Patients With Cancer, Am J. Geriatr Psychiatry. 2018 May; 26(5):523-531, at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6345171/>

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directives for very sick patients and have become familiar with the types of issues that commonly arise in medical treatment disputes. Based on this experience, I have some thoughts about how to draft advance directives that would be more useful in a hospital setting and provide better clarity about the patient's wishes when difficult decisions need to be made.

This article has two goals. The first is to provide information about hospital dispute resolution processes that is little known outside of medical circles but could be crucially important to your clients. This information will help attorneys provide advice and counsel if they are called by a hospitalized client or their family about a medical treatment dispute.

Disputes are not uncommon between patients, their families, and their medical team, especially around the issue of medical futility. There is some evidence to suggest that these disputes are becoming increasingly common, perhaps because there is a lower level of trust in and respect for institutions and professionals and rampant misinformation. Courts rarely get involved in these issues, meaning that resolution occurs within the hospital dispute resolution process.

Second, I will make recommendations about drafting more effective advance directives and health care proxies. Most advance directives are limited to situations where the patient is terminally ill or permanently unconscious or are ambiguously worded and difficult to interpret or use in end-of-life patient situations. These include changes in wording of directions in advance directives, further discussion with both principals and agents, and possibly considering dispensing entirely with the use of Living Wills because they do not work to improve patient-centered decision making.

A. A BRIEF, NECESSARY HISTORY OF THE LAW AND ETHICS OF END-OF-LIFE DECISION MAKING.

Today, virtually all hospitals in the United States have ethics consultation services to assist in resolution of medical treatment disagreements.⁴ Further, in New York, we also have a

⁴ Tapper EB. Consults for Conflict: The History of Ethics Consultation. *Proc (Bayl Univ Med Cent)* 2013;26(4):417-422, 417 (81% of hospitals and 100% of hospitals with more than 400 beds have ethics consultation services).

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legal requirement that health care facilities create an ethics review committee process for handling of intractable disputes.⁵ However, before we get to the details of the process, it would be helpful to go back fifty years for a brief history lesson on how we got to this point.

Starting around 1970, “high tech” medicine and patient rights collided in a series of court cases in which families of permanently unconscious patients, objected to the use of life-sustaining treatment, in most cases ventilators, to keep their loved ones alive. Perhaps the best known of these early cases is In re Quinlan, in 1976, in which the New Jersey Supreme Court, grappled with the request of the father of Karen Ann Quinlan, a young woman who was permanently unconscious (in a persistent vegetative state (PVS)) to remove her from a mechanical ventilator.

The primary issue before New Jersey’s highest court in Quinlan case was whether life-sustaining treatment could be removed from a patient who lacked decision-making capacity and who had not made their wishes known about treatment at an earlier time when they had capacity. The court held that patients have a constitutional “right to privacy” to decline medical treatment and that, when a patient lacks capacity, this right can exercised by a patient’s guardian with medical support that the there was no reasonable possibility of recovery. In re Quinlan, 70 NJ 10, 355 A2d 647, 672 (1976). This was also the first time that a court had recommended that a hospital rely on an ethics committee to make these determinations and provided clinicians with legal immunity from suit if they followed this process.

There were similar cases in other states in which families sought to remove life-sustaining treatment from patients who were permanently unconscious who were terminally or irreversibly ill with no reasonable hope of recovery.⁶ These cases popularized the use of Living Wills as a means for people to make their wishes known about medical treatment they did and

⁵ NY Public Health Law §2994-m (part of Family Health Care Decisions Act passed in 2010).

⁶ Meisel, A. Quality of Life and End-of-Life Decisionmaking. *Vol. 12, Supplement: Multidisciplinary Perspectives on Health-Related Quality of Life* (Springer, 2003), pp. 91-94.

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did not want.⁷ Legally approved documents which also made it possible for patients to appoint an agent to make health care treatment decisions did not exist until the 1980s and 1990s, with New York's Health Care Proxy law being enacted in the early 1990s. Until then, the Living Will was the only judicially approved way for a patient to write down their wishes about medical treatment they did not want.

What had changed? Why were these cases coming to court? There were two primary reasons:

1. Advances in ICU care (e.g. mechanical ventilators, resuscitation techniques, artificial nutrition/hydration) made it possible to keep very sick patients with low quality of life and little chance of recovery alive for extended periods and sometimes indefinitely; and
2. Increasing awareness of the right of patients to make their own treatment decisions and provide an informed consent to medical treatment. The right of a competent patient right to provide consent to medical treatment, recognized elsewhere in society as inherent in the concepts of liberalism and self-determination, came late to medicine. It was not until the early 20th century that courts began to recognize that a patient must have a right to consent and it took many more decades before the modern concept of an informed consent took form.⁸

A. NEW YORK CASES.

New York cases decided by the Court of Appeals in the 1980s set the stage for the passage of the Health Care Proxy law in New York.⁹ In a series of cases, the New York Court of Appeals recognized the right of competent adults to decline life-sustaining treatment. However, the court also set a very high standard for determining that a person did not want treatment –

⁷ Baron, J. Fixed Intentions: Wills, Living Wills, and End-of-Life Decision Making. *87 Tenn L Rev* 375, 380-386 (Winter 2020).

⁸ Rothstein M. The Role of Law in the Development of Bioethics. *J Int Bioethique* 2009 December; 20(4):73-111 (pp. 2-3 for background on patient's rights, p. 5 for discussion of "high tech" medicine).

⁹ NY Public Health Law, Article 29-C Health Care Agents and Proxies, §§2980 – 2994 (1992).

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the party seeking to end life-sustaining treatment needed to prove the subjective specific intent of the patient to the clear and convincing evidentiary standard. General sentiments expressed by a person that they wouldn't want life-sustaining treatment were not enough. Rather, there needed to specific proof that the individual would not have wanted the medical treatment at issue.

- In Re Storar (1981) – People can decline life-sustaining treatment. If a patient now lacks decision-making capacity, life-sustaining treatment can only be withdrawn or withheld if the person made their wishes known earlier at a time when they had decision making capacity. Need clear and convincing evidence.
- Matter of Westchester County (O'Connor case) (1988). Clear and convincing a very high burden. Much criticized. New York went in a different direction than most states in requiring a high level of proof.

An important case decided by the U.S. Supreme Court is Cruzan v. Director, Missouri Dept. of Health, 497 US 261 (1990). In Cruzan, the Court found a constitutional liberty interest in refusing life-sustaining treatment (in Cruzan, artificial nutrition and hydration). It also upheld the right of states to use the clear and convincing evidence standard as the basis for proving a patient's wishes.¹⁰

B. EARLY BEGINNINGS OF THE USE OF ETHICS COMMITTEES

The first modern use of an ethics committee, which some have also called the birth of modern bioethics, was the creation in 1961 of the “God Committee” at Seattle Swedish Hospital to make recommendations on who should get first priority in receiving kidney dialysis, which had just been developed and was a limited resource.¹¹ We also saw in the 1960s the

¹⁰ See, Pence, GE. *Classic Cases in Medical Ethics: Accounts of the Cases and Issues that Define Medical Ethics* (McGraw Hill, 5th Ed.), ch. 2, Comas (overview of medical, legal and ethical issues involving Quinlan, Cruzan and Shiavo cases. In all three cases, the patients were in long-term comas with medical opinion being that they had no reasonable hope of recovery).

¹¹ Weinberg, JK. Institutional Ethics Committees: Should We Kill All the Lawyers – The Role of Lawyers on Hospital Ethics Committees. 21 *Annals Health L.* 181, 182 – 183 (2012).

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creation by hospitals of therapeutic abortion committees, dialysis committees, and early institutional review boards.¹²

Beginning in the 1970s, hospitals and other health care facilities started creating ethics committees and using ethics consultants to assist in resolving medical treatment disputes.¹³ The Quinlan court decision in 1976 recommending the use of ethics committees to determine “general practice or procedure” also sped up the process.¹⁴ Their use was further boosted by a 1983 report, “Deciding to Forgo Life-Sustaining Treatment,” issued by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, which also included a model statute for ethics committees.¹⁵

Since 1992, all hospitals are required as part of their accreditation process by the Joint Commission on Accreditation of Healthcare Organization (JACHO) to have an internal mechanism for ethics review.¹⁶ In New York, every hospital is required by law to have an ethics review committee.¹⁷

The impetus behind the creation of an internal hospital ethics review process came from growing legal, medical, philosophical, legislative, and public consensus that people can reasonably disagree about whether a life-sustaining treatment should or should not be used and that courts were not best equipped to resolve these disputes.¹⁸

¹² Pope TM, Legal Briefing: Healthcare Ethics Committees. *The Journal of Clinical Ethics*. Vol. 22. No. 1 (Spring 2011):74-93.

¹³ Annas, G and Grodin, M. Second Thoughts: Hospital Ethics Committees, Consultant and Courts, *AMA Journal of Ethics*, May 2016, Vol. 18, No. 5:554-559.

¹⁴ Pope TM, Legal Briefing: Healthcare Ethics Committees. *The Journal of Clinical Ethics*. 22 No. 1 (Spring 2011):74-93.

¹⁵ *Id.*

¹⁶ Annas, G and Grodin, M, Second Thoughts: Hospital Ethics Committees, Consultant and Courts. *AMA Journal of Ethics*. May 2016, Vol. 18, No. 5:554-559.

¹⁷ NY Public Health Law §2994-m (part of Family Health Care Decisions Act passed in 2010).

¹⁸ See, Aulisio M, History of Medicine: Why Did Hospital Ethics Committees Emerge in the US? *AMA Journal of Ethics*, May 2016, Volume 18, Number 5:546-553, at <https://journalofethics.ama-assn.org/article/why-did->

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Courts struggled with resolving end-of-life treatment disputes because, at their essence, these cases are nearly impossible to decide because the question whether a treatment is beneficial or futile often comes down to a value judgment.¹⁹ Efforts such as the 1980s Uniform Health-Care Decisions Act (UHCDCA) failed because they were unable to define the undefinable – what is a beneficial medical treatment and what is medically futile?²⁰ If a treatment keeps a patient alive, no matter how poor the quality of life, people can differ on whether this is a medically effective treatment.²¹ Families in these situations are often hoping for a miracle that the medical team believes, based on their medical knowledge and experience, will not happen. Pitted against the family’s insistence on treatment is the clinician’s professional obligation to provide treatment that is medically beneficial.²² In other cases, physicians have objections of conscience, based on religious or moral beliefs, to continuing treatment that is causing suffering to a patient who will die soon, whether or not treatment is provided.²³

Courts and the judicial process have often moved too slowly to resolve medical treatment decisions for seriously ill patients whose medical condition can change dramatically

[hospital-ethics-committees-emerge-us/2016-05](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3777084/); see also, Tapper, Eliot B., Consults for Conflict: the History of Ethics Consultation. *Proc (Bayl) Univ Med Cent*. 2013;26(4):417-422, at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3777084/>

¹⁹ Clark PA. Medical Futility: Legal and Ethical Analysis, *AMA Journal of Ethics, Virtual Mentor*. 2007;9(5):375-383. doi: 10.1001/virtualmentor.2007.9.5.msoc1-0705.., at <https://journalofethics.ama-assn.org/article/medical-futility-legal-and-ethical-analysis/2007-05> (“Determining whether a medical treatment is futile basically comes down to deciding whether it passes the test of beneficence; that is, will this treatment be in the patient’s ‘best interest’? [This] involves value judgments by both the patient and the physician.”).

²⁰ Baldassarri, SR, Lee I, Latham, S and D’Onofrio G. Debating Medical Utility, Not Futility: Ethical Dilemmas in Treating Critically Ill People Who Use Injection Drugs. *J Law Med Ethics*. 2018 June; 46(2):241-251.

²¹ *Id.*

²² Pope TM. Symposium Article: Procedural Due and Intramural Hospital Dispute Resolution Mechanisms: The Texas Advance Directive Act.” *10 St. Louis U.J. Health L & Pol’y* 93, 103 (2016).

²³ Pope TM. Freedom of Choice at the End of Life: Patient’s Rights in a Shifting Legal and Political Landscape: Dispute Resolution Mechanisms for Intractable Medical Futility Dispute. *58 NYL Sch L* 347, 363 (2014) (“Because some clinicians equate the administration of ‘futile’ treatment with torture and inhumanity, they may make conscience-based refusals pursuant to [state health care conscience clause] laws.”).

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from minute to minute.²⁴ As dissatisfaction grew with judicial resolution, with even judges noting that they were not well equipped to handle end-of-life treatment cases, there was growing consensus that these disputes would be better handled by an internal hospital process of consultation, with the goal being assisting disputants in reaching agreement rather than a judicial process where a judge makes the final decision and there is a winner and loser.²⁵

C. NEW YORK LEGISLATIVE DEVELOPMENTS – Creation of the Health Care Proxy form (1992) and the Family Health Care Decisions Act (FHCDA) (2010).

There was broad dissatisfaction in New York with the decisions by the New York Court of Appeals in the 1980s because they made it nearly impossible to withhold or withdraw life-sustaining treatment from dying patients, even those who had expressed wishes but not specifically or clear enough to pass the Court's high bar. As a result, the first Governor Cuomo created the New York State Task Force on Life and the Law (Task Force) to make recommendations on changing New York law (the Task Force has also issued reports on other important health care legal, medical and ethical issues).

²⁴ Id., at 360 – 361 (2014) ([J]udges preserve the status quo (the administration of life-sustaining treatment) . . . The judicial process is so slow and cumbersome that the patient often dies before the court reaches the merits of the dispute.”); see also, Luce JM, Alpers Ann, “Legal Aspects of Withdrawing Life Support from Critically Ill Patients in the United States and Providing Palliative Care to Them.” *Am J Respir Crit Care Med*, Vol. 162 (2000):2029-2032 (“The history of legal cases involving futility has been that courts have almost uniformly order continued treatment when asked to resolve disputes between families who favor treatment and physicians who oppose it. . . Judges also seem unwilling to cause the death of a patient . . .”); see also, Powell, T and Lipman, H. Bioethics Consultation Before and After the Family Health Care Decisions Act. *NYSBA Health Law Journal*, Spring 2011, Vol. 16., No. 1, 71 – 75, 73, at <https://nysba.org/NYSBA/Publications/Section%20Publications/Health/PastIssues1996present/2011/2011Assets/HealthJrnSpr11.pdf>

²⁵ See, Pope TM. Legal Briefing: Healthcare Ethics Committees. *The Journal of Clinical Ethics* 22. No. 1 (Spring 2011): 74-93; see also, American Medical Association, Ethics Consultations, Code of Medical Ethics Opinion 10.7.1, at <https://www.ama-assn.org/delivering-care/ethics/ethics-consultations#:~:text=Code%20of%20Medical%20Ethics%20Opinion%2010.7.,-1&text=Whether%20they%20serve%20independently%20or,the%20patient's%20needs%20and%20values.>

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In 1987, the NYS Task Force issued a report recommending the creation of the health care proxy form.²⁶ Its recommendations formed the basis for the Health Care Proxy, which became law in 1992.²⁷ With its passage, a competent person could appoint someone to make health care decisions for them when they were no longer able. That person could also add specific directions in the HCP form about future health care treatment they did or did not want. Further, it empowered the Health Care Proxy agent to consent to withdrawal of most life-sustaining treatment based on the patient's wishes, values and preferences (the agent had to know the patient's actual wishes in order to end artificial nutrition and hydration).

The New York State Task Force also made recommendations in a later report supporting legislation creating a process for appointment of surrogate decision makers (a list of family members in a hierarchy based on closeness to the patient) for people who did not complete a health care proxy. These recommendations led, in 2010, to the passage of the New York Family Health Care Decisions Act (FHCDA). As a result, we now have a legal process in New York for people to appoint their own HCP agents or, if they fail to do so, for a surrogate decision maker to be appointed for them. This will be covered in detail by another presenter.

D. SUMMING UP – HOW WE GOT TO WHERE WE ARE TODAY.

This richly textured history has led us to where we are today:

1. Beginning in the late 1960s, the living will became popularized;²⁸
2. New York passed the Health Care Proxy Law in 1992 and today all states have created similar documents that permits people to appoint someone to make medical decisions for them;²⁹

²⁶ The New York State Task Force on Life and the Law, *Life-Sustaining Treatment: Making Decisions and Appointing a Health Care Agent* (July, 1987), at https://www.health.ny.gov/regulations/task_force/reports_publications/docs/life-sustaining_treatment.pdf

²⁷ New York Public Health Law, Article 29-C, §§2980 – 2994.

²⁸ Baron, J. Fixed Intentions: Wills, Living Wills, and End-of-Life Decision-Making. *87 Tenn L Rev* 375, 379 – 380) (Living Will was first proposed in a 1969 article by Luis Kutner, an international human rights lawyer).

²⁹ Olick, RS. Defining Features of Advance Directives in Law and Clinical Practice. *Chest* 2012; 141(1):232-238.

3. Ethics consulting and ethics committees developed in response to growing consensus that hospitals needed an internal dispute resolution process and are now required as part of hospital accreditation;
4. The NY Family Health Care Decisions Act was passed in 2010 and created a process for appointment of surrogate decision makers to make treatment decisions for patients who failed to sign a HCP (decisions are based on the wishes, values and preferences of the patient, if known, and if not then based on the best interest of the patient);³⁰
5. The NY FHCDA adds an ethics review committee process for intractable disputes, which is essentially a mediation process as a last resort after ethics consultation failed and before judicial intervention; and
6. The Medical Order for Life-Sustaining Treatment (MOLST) form is required in New York (and many other states) and requires that clinicians meet with patient with serious illnesses and complete the form to determine what their wishes are about specific life-sustaining treatments.

II. HOSPITAL DISPUTE RESOLUTION IN NEW YORK – HOW DOES IT WORK?

In hospitals and health care facilities across the country, medical treatment disputes are generally first referred to an ethics consultant for attempted resolution. Since 1992, an ethics review process has been required as part of hospital national accreditation by JCAHO.³¹ This is almost always going to be provided by an ethics consultation service.³² Further, in New York there is also the requirement that hospitals create an ethics review committee to hear ethics disputes and to provide nonbinding advice and recommendations.³³

³⁰ Pope TM. Comparing the FHCDA to Surrogate Decision Making Laws in Other States. *NYSBA Health Law Journal*. Spring 2011, Vol. 16. No. 1, 109-113, abstract at https://papers.ssrn.com/sol3/papers.cfm?abstract_id=1797930

³¹ Chaet, D. The AMA Code of Medical Ethics' Opinions on Ethics Committees and Consultations, *AMA Journal of Ethics*, May 2016, Vol. 18. No. 5:499-500, at <https://journalofethics.ama-assn.org/sites/journalofethics.ama-assn.org/files/2018-05/coet1-1605.pdf>

³² Tapper E. Consults for Conflict: The History of Ethics Consultation, *Proc(Bayl) Univ Med Cent*) 2013;26(4):417-422 (81% of hospital and 100% of hospitals with more than 400 beds use ethics consultants).

³³ New York Public Health Law §2994-m.

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Most end-of-life treatment disputes will be resolved by continued communication and discussion with the family, sometimes aided by deterioration in the patient's condition.³⁴ Ethics consultation services, staffed by experienced and trained ethics consultants, can step in to provide informal mediation services and provide an ethical perspective of the issues. Although there is little information known about how they work in practice, they are believed to be very successful at amicably resolving disputes.³⁵ However, after all this, there will still be cases, estimated at about 5% of disputes, where agreement cannot be reached.³⁶

A. ETHICS CONSULTATION.

The first step in hospital dispute resolution is generally a request made to the hospital's ethics consultation service. Hospitals either maintain their own ethics consultation service or contract with another hospital or group. Consultants come from a variety of backgrounds, primarily the medical and nursing fields, but also including people with backgrounds in philosophy, public health, social work and law. Lawyers make up a small percentage of ethics consultants. However, interestingly, a New York City attorney, Nancy Dubler, is widely credited with popularizing the modern-day ethics consulting field.³⁷

In practice, a request is made by a member of the medical team, a patient or their family to the ethics consultation service at the hospital where the patient is hospitalized. Most times, the request is made by a telephone call to the ethics consultant on duty. Although most

³⁴ Pope TM. Freedom of Choice at the End of Life: Patient's Rights in a Shifting Legal and Political Landscape: Dispute Resolution Mechanisms for Intractable Medical Futility Dispute. 58 *NYL Sch L* 347, 355 (2014) at 355 (Over 95% of medical futility disputes are resolved through continued communication and mediation).

³⁵ Pope TM and Kemmerling K. Legal Briefing: Stopping Nonbeneficial Life-Sustaining Treatment Without Consent. *The Journal of Clinical Ethics*, Vol. 27, No. 3 (Fall 2016):254-264.]

³⁶ Pope TM and Kemmerling K. Legal Briefing: Stopping Nonbeneficial Life-Sustaining Treatment Without Consent. *The Journal of Clinical Ethics*, Vol. 27, No. 3 (Fall 2016):254-264.]

³⁷ One of the first books on bioethics mediation was co-authored in 2004 by Nancy Dubler with Columbia University Law Professor Carol Liebman. Titled *Bioethics Mediation: A Guide to Shaping Shared Solutions*, it was updated in 2011, a description of the book can be found at <https://www.scribd.com/book/251905135/Bioethics-Mediation-A-Guide-to-Shaping-Shared-Solutions-Revised-and-Expanded-Edition>

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calls are from a member of the medical team, anyone involved with a patient's cases can call, including patients themselves or their families.

If you google a particular hospital and the term "ethics consultant," you should find links for the ethics consultation service for the hospital.

Here are two examples:

- Northwell Health -
<https://professionals.northwell.edu/departments/medicine/divisions/medical-ethics/programs-services>
- Albany Medical Center -
https://www.amc.edu/academic/bioethics/ethics_consult.cfm#:~:text=To%20request%20a%20research%20ethics,or%20518%2D262%2D9396.&text=Patients%2C%20families%2C%20and%20healthcare%20providers,needed%20in%20making%20difficult%20decisions.

The primary goal of an ethics consult is to determine the patient's wishes and ensure that they are respected and, if not known, that decisions are made in the best interest of the patient.³⁸

Ordinarily, a consult is requested by a clinician when they perceive that an ethical problem has arisen in the care of a patient, usually resulting from disagreement between the team and the patient or surrogate about the next course or action.³⁹ An ethical dilemma occurs when there is a conflict between two ethical principles or between principles and outcomes.⁴⁰ A common example would be where the patient has completed an advance directive saying that they want care to stop under certain circumstances and the patient's surrogate continues to push for aggressive treatment.

³⁸ See, University of Washington, Dept. of Bioethics & Humanities, at Ethics Committees and Consultation, at <https://depts.washington.edu/bhdept/ethics-medicine/bioethics-topics/detail/64#:~:text=At%20UWMC%2C%20the%20ethics%20consultant,ethics%20consultation%20service%20pager%2C%20206.762.>

³⁹ Id.

⁴⁰ Id.

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The ethic consultant answers questions, provides an ethical perspective, and works with the stakeholders toward a principled agreed-upon resolution of the issues. Consultant may also provide navigational assistance when an issue can better handled by another hospital department or outside source. Importantly, consultants do not “decide” issues. They don’t impose their values on the parties. Rather, they help stakeholders to “determine the range of ethically and legally acceptable choices and work to facilitate a consensus within that framework.”

Consultants focus first on determining the wishes, values and preferences of the patient. This includes looking at any advance directives completed by the patient, including MOLST forms, DNR wishes, or directions in a Living Will or Health Care Proxy. They will also speak with various team and/or family members, including the patient if the patient is able, to determine the patient’s wishes, patient’s medical condition, various treatment options, and sources of disagreement.⁴¹ The consultant may ask for a meeting with the medical team, with the patient and family, or a combined meeting. The consultant can highlight ethical issues, take a fresh look, and provide nonbinding advice and recommendations.

Much of what ethics consultants do is a form of informal mediation. They follow the same HIPAA rules protecting patient confidentiality as other hospital staff. Here are a couple of articles that provides a good description of the specifics of ethics consulting.^{42 43}

⁴¹ See, Orr RD and Shelton, W. A Process and Format for Clinical Ethics Consultation. *The Journal of Clinical Ethics*, Spring 2009, Vol. 20. No. 1, 1-11, at 4, at <https://adventistbioethics.org/sites/adventistbioethics.org/files/docs/A-Process-and-Format-for-Clinical-Ethics-Consultation.pdf> (provides talking points for an ethics consultation with a patient/surrogate or family, starting with “Now tell me more about what kind of person [the patient] is” to help clarify the patient’s wishes, values and preferences.

⁴² Orr, Robert D and Shelton, Wayne. A Process and Format for Clinical Ethics Consultation. *The Journal of Clinical Ethics*. Vol. 20, No. 1, at <https://adventistbioethics.org/sites/adventistbioethics.org/files/docs/A-Process-and-Format-for-Clinical-Ethics-Consultation.pdf>

⁴³ Powell T and Lipman, H. Bioethics Consultation Before and After the Family Health Care Decisions Act. *NYSBA Health Law Journal*, Spring 2011, Vol. 16., No. 1, 71-75, at <https://nysba.org/NYSBA/Publications/Section%20Publications/Health/PastIssues1996present/2011/2011Assets/HealthJrnSpr11.pdf>

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How does this differ from standard mediation? First, consultants are generally hospital employees or affiliated with the hospital, although their mission is patient centered. Second, in virtually all ethics consults the patient lacks or has impaired decision-making capacity.⁴⁴ Third, ethics consultants seek a principled resolution, not just any resolution.⁴⁵

B. ETHICAL PRINCIPLES GUIDING ETHICS CONSULTATIONS (SIMILAR BUT DIFFERENT THAN LEGAL PRINCIPLES).

It is also important to note that ethics consultants work with ethical principles. There is a rich body of ethics in medicine that generally mirrors legal principles. However, laws tend not to provide the specific guidance that medical ethics can provide to specific patient bedside issues. There is a rich body of thought and literature in the medical ethics field that provides clearer assistance to medical practitioner and patients and their families alike when dealing with specific treatment disputes.

Briefly, most medical ethics discussions in the modern era are based on a discussion of the following principles the principles of autonomy, beneficence, non-maleficence and justice.⁴⁶

Below I compare ethical principles to legal principles.

ETHICAL PRINCIPLES

Autonomy (includes self-determination, confidentiality, dignity, informed consent, etc.)

Beneficence

Non-maleficence

Justice (fairness, fair distribution of resources)

LEGAL PRINCIPLES

Liberty/freedom

Best Interests – Parens Patriae

Do No Harm – Police Power

Justice (procedural, substantive, very broad meaning)

⁴⁴ Annas G, Grodin M. Second Thoughts: Hospital Ethics Committees, Consultants and Courts. *AMA Journal of Ethics*, May 2016, Vol. 18, No. 5:554-559, at <https://journalofethics.ama-assn.org/article/hospital-ethics-committees-consultants-and-courts/2016-05>

⁴⁵ Dubler, N, Liebman C. *Bioethics Mediation: A Guide to Shaping Shared Solutions* (2011), description at <https://www.law.columbia.edu/news/archive/bioethics-mediation-guide-shaping-shared-solutions>

⁴⁶ See, Varkey B, Principles of Clinical Ethics and Their Application to Practice, *MED PRINC* 2021; 30:17-28, at <https://www.karger.com/Article/FullText/509119>

In most patient bedside issues, the ethics consultant is trying to discern what the patient's wishes are about the medical treatment issue that needs to be made. In New York, both ethically and legally, a patient doesn't have to specifically state what they want. In most cases, patients have not done that. Rather, the key is to determine what the patient's wishes, values and preferences are about medical treatment.

Also, both ethically and legally we can rely on the patient's HCP agent to make these decisions. The HCP agent is charged with making treatment decisions based on what they believe the patient would have wanted. Except for the withholding or withdrawal of artificial nutrition and hydration, they can make this decision based on what they believe the patient would have wanted. For AN&H, they need to specifically know what the patient would have wanted.

C. AN ADDITIONAL REQUIREMENT IN NEW YORK – THE ETHICS REVIEW COMMITTEE UNDER THE FAMILY HEALTH CARE DECISIONS ACT, PHL 2994-m.

What is the next step in New York when there is intractable disagreement about the use or non-use of a life-sustaining treatment? In many states, the next step after an ethics consultation would be to seek court intervention. In New York, however, an important but little-known provision in the Family Health Care Decisions Act (FHCDA) provides that hospitals and other health care facilities must set up an Ethics Review Committee (ERC) for review of intractable medical treatment disagreements.⁴⁷

In most New York hospitals, the ERC is an extra layer of internal hospital review that is available after an ethics consultation. The functions of the ERC can be carried out by an existing hospital committee by a specially created hospital committee or by an ERC that serves more than one hospital, as long as the requirements of the statute are met.⁴⁸ In some hospitals, it needs to be distinguished from the hospital ethics committee, which provides various policy overview and educational functions for the institution. In any case, the hospital needs to create a hospital policy describing how it will satisfy the law's requirements.

⁴⁷ NY Public Health Law §2994-m (part of Family Health Care Decisions Act that passed in 2010).

⁴⁸ Id.

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The ERC provides advice, “recommendations [,] . . . advice . . . and other assistance in resolving disputes about proposed health care.”⁴⁹ It is ordinarily the last step in the internal dispute resolution process before a lawsuit. As with ethics consultation, the goal of the ERC process is to develop common ground for the parties without supplanting the authority of the authorized decision maker to make the final decision. However, there is nothing stopping a patient, family or other stakeholder from proceeding directly to a lawsuit.

The legislation provides that the ERC must have a specific composition of people of different professions and include a member of the public without any relationship to the hospital.⁵⁰

ERCs have broad authority and responsibility to respond to any request for assistance in resolving “any health care matter” by “a person connected with the case,” which is defined to include pretty much everyone who has an interest in a patient.⁵¹

In most cases, the ERT provides nonbinding advice and recommendations.⁵² For instance, in the most common type of treatment disagreement, where the surrogate decision maker wants to continue treatment and the medical team disagrees on the basis that it would be medically futile to do so, the ERC works in an advisory and nonbinding capacity.

There are however, limited instances when the ERT’s decisions are binding, including when there is clinician disagreement with an FHODA surrogate’s decision to forego artificial nutrition and hydration and to confirm that statutory standards were followed when an emancipated minor chooses to withhold or withdraw life-sustaining treatment.⁵³

⁴⁹ Id., at 2994-m (2)(b).

⁵⁰ Id., at 2994-m(3).

⁵¹ Id., at 2994-m (20(a); “person connected with the case” defined at 2994-a (26).

⁵² Id., at 2994-m(2)(c).

⁵³ Id.; see also 2994-g (5)(c) (ERC must conform that a 2-physician determination to withhold or withdraw life-sustaining treatment for an incapacitated patient without a surrogate “is consistent with such standards for surrogate decisions; see also 2994-g(6)(if the clinician providing a concurring opinion disagrees with a decision to end life-sustaining treatment for an incapacitated patient without a surrogate, it “shall” be referred to the ERC.

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The ERT must promptly hear matters referred to it. It must also give notice of its meeting and provide its response to anyone connected with the case. Anyone connected with the case has the opportunity to present their views before the ERT responds, including the right to be “accompanied by an advisor.”⁵⁴

A takeaway point is that the patient, their surrogate decision maker, and pretty much any involved family can ask for an ERC review. Further, the right of a person involved in a case to bring an “advisor” with them is expressly permitted.⁵⁵

D. OTHER STATES.

It bears mentioning that New York is not alone in mandating hospital ethics committee review. Other states have passed a variety of laws, ranging from giving ethics committees binding power to unilaterally terminate life-sustaining treatment with clinician with immunity from litigation (Texas), to providing ambiguous guidance that permits ethics committee termination of treatment but is unclear about clinician immunity (California), to states like New York that require a process but limit the ethics committee to giving primarily nonbinding advice and guidance.⁵⁶ Many of these laws can be traced to the Uniform Health-Care Decisions Act (UHCDA), which was a 1980s initiative to provide clinicians with limited authority to unilaterally end life-sustaining treatment that was “medically ineffective” and “contrary to applicable health-care standards.”⁵⁷ “Medically ineffective” treatment was further described as treatment that did not provide the patient with a “significant benefit.”⁵⁸ However, whether a treatment

⁵⁴ PHL 2994-m (4)(b)(ii) (“The committee shall permit persons connected with the case to present their views to the committee, and to have the option of being accompanied by an advisor when participating in a committee meeting.”).

⁵⁵ *Id.*

⁵⁶ Pope TM. Dispute Resolution Mechanisms for Intractable Medical Futility Disputes. 58 *NYL Sch L* 347 (2013).

⁵⁷ National Conference of Commissioners on Uniform State Laws. Uniform Health-Care Decisions Act. *Issues in Law & Medicine* 22, No. 1 (2006).

⁵⁸ *Id.*

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provides a “significant benefit” has proved elusive to define because reasonable people can disagree about what that means.⁵⁹ In Texas, which is the only state that has fully empowered ethics committees to make decisions to end care over patient family objection, the law has been subject to numerous court challenges and been heavily criticized by scholars.⁶⁰

E. COMMON ISSUES THAT ARISE IN ETHICS CONSULTS.

As discussed below, there can be numerous difficulties in interpreting advance directives at the bedside. This is due in part to difficulty following patient wishes in a dynamic clinical environment, understanding patient wishes when they are written broadly in a legal document, such as a living will which is often executed well in advance of the patient’s current hospitalization and medical condition. In many consults, either the agent or the medical team has a mistaken notion about the patient’s health care proxy or other advance directive, what it says and when it applies. However, underlying many disputes is a fundamentally different understanding between agents and the medical team, which comes down to whether, in our modern era of medical decision making based on patient rights and self-determination, does the physician have any say into that decision-making process?

The goal of the ethics consultant, applying medical ethical principles, is to provide guidance that leads the parties to a resolution based on the patient’s wishes. This closely follows the legal principle of the right of patient self-determination. As discussed below, there can be numerous difficulties in interpreting advance directives at the bedside. This is in part due to difficulty following patient wishes in a dynamic clinical environment, understanding patient wishes when they are written broadly in a legal document, such as a living will, executed well in advance of the patient’s current hospitalization and medical condition. In many consults, either the agent or the medical team has a mistaken notion about the patient’s health care proxy or other advance directive, what it says and when it applies. However, underlying many disputes is a fundamentally different understanding between agents and the

⁵⁹ Pope TM. Medical Futility Statutes: No Safe Harbor to Unilaterally Refuse Life-Sustaining Treatment. 75 Tenn L Rev 1 (2007).

⁶⁰ Id.

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medical team, which comes down to whether, in our modern era of medical decision making based on patient rights and self-determination, does the physician have any say into that decision-making process?

Agents often have a misunderstanding about their powers, especially when it involves agreeing to ending life-sustaining treatment. Likewise, physicians can also be confused about what to do, especially when looking at conflicting statements by a patient and/or an agent about what to do. Underlying it all is a fundamental differing perspective between agents and physicians in cases where the patient is critically but not terminally ill and needs life-sustaining treatment.

Here are some common issues that are seen with making medical treatment decisions for seriously ill hospitalized patients.

1. HCP agent wants everything done and the medical team has done everything it believes is beneficial. This is the classic medical futility issue.
2. Specific common subset of #1 - Family refuses to agree to a DNR for a terminally ill patient and medical team believes it is torture to continue to do DNR.
3. The opposite of #1 (less frequent) – the medical team wants to treat and the family says no. This commonly occurs where the medical team believes the patient has a good chance of a full or substantial recovery.
4. Other issues – conflict between what the surrogate or other family member wants and other evidence of the patient’s wishes.
5. Conflict between documents in determining what the patient’s wishes are (Living Will v. MOLST v. DNR).
6. Patient has questionable capacity and is refusing treatment without which the patient could die. Alternate scenario is patient with questionable capacity seeking to leave the hospital Against Medical Advice (AMA), creating a life-threatening health risk for the patient.
7. All sorts of issues with patients under age 18 – when can they consent, when do parents have the legal right to consent, parents direct that the clinicians not tell the patient about their medical condition, parents refuse treatment that is in the best interest of the patient, patient under 18 refuses lifesaving treatment, etc.

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8. Myriad other issues – organ transplant issues, brain death disagreement, duty to warn cases, questions about bad faith of surrogates, making decisions for incapacitated patients without surrogates, clinical trial access for patients who lack a surrogate, questions for governmental adult protective services because of concern about abuse, resource allocation (eg. ventilators, blood products), etc.

II. LIVING WILLS – HOW WELL DO THEY WORK IN PRACTICE?

Abstract: Living Wills, in which people document their preferences about the use of life-sustaining medical treatment, have long been a part of the legal landscape in New York, first finding their footing after the Court of Appeals made it clear in the 1980s that treatment could only be withheld or withdrawn based on clear evidence of the patient's wishes. The HCP was later created. However, attorneys still write living wills. Little is written in legal literature about how well they work. This article will argue that they are of limited use in resolving medical treatment disputes and can muddy the water about what the patient's real intentions are. The author will provide recommendations for more precise drafting of living wills or forgoing it and relying on the Health Care Proxy form and the Medical Order for Life-Sustaining Treatment (MOLST) form for optimal medical decision making in line with patient wishes, values and preferences.

A. LIVING WILLS – WHAT ARE THE PROBLEMS SEEN WITH HOSPITALIZED PATIENTS?

Living Wills are a staple of attorney estate planning for their clients. However, how well do they work to ensure that the patient's wishes are followed? As described below, there are many issues with using them to determine patient wishes which have been pointed out in academic articles,⁶¹ practicing lawyers,⁶² and practicing physicians.⁶³

⁶¹ See, Sabatino CP. The Evolution of Health Care Advance Planning Law and Policy. *Milbank Quarterly*. Vol. 88, No. 2, 2010 (pp. 211-239); see also, Fagerlin A, Schneider CE. Enough: The Failure of the Living Will, *Hasting Center Report* 34. No. 2 (2004): 30-42.

⁶² Franklin M, Phelps G. Advance Care Planning: When Law and Medicine Intersect. *Tennessee Bar Association, TBA Law Blog*, 2/1/16, at <https://www.tba.org/index.cfm?pg=LawBlog&blAction=showEntry&blogEntry=23817>

⁶³ See, Karan A, Code Blue Confusion: He'd Checked 'Do Not Resuscitate' But Wanted to Live, *WBUR*, 10/30/17, at <https://www.wbur.org/news/2017/10/30/end-of-life-dnr-code-status>; see also, Graham J. That 'Living Will' You Signed? At the ER, It Could Be Open to Interpretation, *Kaiser Health News*, 6/14/18, at <https://khn.org/news/that-living-will-you-signed-at-the-er-it-could-be-open-to-interpretation/>; see also, Groopman J, Hartzband P. Advance

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1. They are often many years old and written before the patient became ill.
2. They are often written in a limited way – apply only if patient is terminally ill or in a permanently unconscious position. These are not the hard cases. However, most ethics consults occur on the continuum between well and terminally ill and living wills are not very useful in determining what the patient would want to do in these circumstances.

For example, writer Amy Bloom’s husband, in the early stages of Alzheimers, opted for Medical Assistance in Dying (MAID) but did not qualify in any states in the United States because he was not terminally ill. He went to another country instead.⁶⁴

As another example, see this article in the New York Times by Dr. Daniella Lamas – “What happens when it becomes clear that a patient is not actively dying, but not getting better either? How do doctors and family members navigate death when it is not imminent and unavoidable, but is instead a decision?”⁶⁵

3. Similarly, Living Wills are often written in “legalese” and hard to interpret. There is little evidence that they accurately predict a patient’s future preferences.⁶⁶
4. FYI, there is evidence that they get misinterpreted to mean comfort care in all instances.⁶⁷
5. Living Wills can be hard for clinicians to find when the patient is in the hospital.

Directives Are The Beginning of Care, Not The End, *ACP Internist*, July/August 2012, at <https://khn.org/news/that-living-will-you-signed-at-the-er-it-could-be-open-to-interpretation/>

⁶⁴ Bloom, Amy. *In Love: A Memoir of Love and Loss* (2022), at <https://www.amazon.com/Love-Memoir-Loss/dp/0593243943>

⁶⁵ Lamas, DJ. In the ICU, Dying Sometimes Feels Like a Choice, *NYT*, July 29, 2022, at <https://www.nytimes.com/2022/07/31/opinion/icu-death-family-choice.html?referringSource=articleShare>

⁶⁶ Kurin M and Mirarchi F. The Living Will: Patients Should Be Informed of the Risks. *American Society for Healthcare Risk Management*. Vol. 41, No. 2 (2021) at section “Mutability of Treatment Preferences.”

⁶⁷ Graham J. That ‘Living Will’ You Signed? At the ER, It Could Be Open to Interpretation. *Kaiser Health News*, June 14, 2018, at <https://khn.org/news/that-living-will-you-signed-at-the-er-it-could-be-open-to-interpretation/>

6. They can also be contradicted by more recent documents, such as a MOLST form, or by a HCP agent who says that this is not what she/he would have wanted. HCPs are empowered to make decisions, including decisions to withdraw or withhold, but what can be done if the HCP wants something done that is at odds with an earlier document.

A. AN ADDITIONAL PROBLEM: NON-MEDICAL PEOPLE HAVE MISCONCEPTIONS ABOUT THE USE OF LIFE-SUSTAINING TREATMENT.

1. Many non-medical people think (both patients and agents) that life-sustaining treatment is only used when the patient is terminally ill and near death. Not so. For example, a patient could have a temporary feeding tube because of nausea after a surgery that will likely eventually improve.⁶⁸
2. Most patients, when polled, will say they want life-sustaining treatment if they have a good chance at recovery.⁶⁹ There is also evidence that health care agents predictions of the patient's wishes are little better than chance.⁷⁰ However, on the other hand, many people delegate these decisions to their agents without specific directions because they trust them to make the right decisions.⁷¹
3. Many doctors believe that patients who have a good chance at recovery would want that chance.⁷²

⁶⁸ Karan A. Code Blue Confusion: He'd Checked 'Do Not Resuscitate' But Wanted to Live, *WBUR*, October 30, 2017, at <https://www.wbur.org/news/2017/10/30/end-of-life-dnr-code-status>

⁶⁹ "Regardless of what patient put on these forms, they probably want to be treated for any condition for which recovery is possible." Philip Betbeze. Physician: 'I Almost Killed a Patient Because of an Advance Directive. May 2, 2014, at <https://www.healthleadersmedia.com/strategy/physician-i-almost-killed-patient-because-advance-directive?page=0%2C3> (Dr. Ferdinando Mirarchi says his father died of sepsis because the medical team interpreted a DNR order to mean that he was not to be treated for bedsores).

⁷⁰ Garner, KK, Lefler LL. Kirchner JD and Sullivan D. Surrogate Decision Making: Medical and Legal Implications for Healthcare Providers, *Consultant 360*, Vol. 18, No. 07, July/August 2010, at <https://www.consultant360.com/articles/surrogate-decision-making-medical-and-legal-implications-healthcare-providers>

⁷¹ Fagerlin, A, Schneider CE. Enough: The Failure of the Living Will. *Hastings Center Rep.* 34, No. 2 (2004): 30-42, 32, fn 31.

⁷² Karan, *supra*.

C. DRAFTING RECOMMENDATIONS.

1. Should attorneys stop using Living Wills? There are plenty of articles arguing that the good they do is outweighed by the bad. See, list, at A.1, above. If your client has executed a recent MOLST form, consider relying on that instead.
2. Or, consider updating Living Wills regularly so that they don't go "stale" as part of advance care planning. One example: Gunderson model.⁷³ Advance care planning is also discussed in this article from the Tennessee Bar Association.⁷⁴
3. Do not limit the application of the Living Will to determination that patient is "terminally ill" or "permanently unconscious." Be as clear about the patient's medical condition as you can and about the treatments that the patient may or may not want. Consider asking the patient: if your doctor's opinion is that you have a good chance of a substantial recovery, do you want that chance? Or would you prefer that your agent under your Health Care Proxy make that decision?
4. Or, add tiebreaker language into the Health Care Proxy to clarify whether to follow the Living Will, a more recent MOLST form, or the HCP agent when there is a question. Legally, courts have not provided clear guidance on whether a living will or the HCP should be followed when there is disagreement between the two.⁷⁵ Either add language that the HCP agent has final authority to make decisions and can override wishes expressed in a living will or elsewhere or that the living will controls.

⁷³ Gunderson Model of advance care planning, at at <https://respectingchoices.org/about-us/history-of-respecting-choices/>

⁷⁴ Franklin, M, Phelps, G. Advance Care Planning: When Law and Medicine Intersect. *Tennessee Bar Association, TBA Law Blog*, Feb 2016 – Vol. 52., No. 2, at <https://www.tba.org/index.cfm?pg=LawBlog&blAction=showEntry&blogEntry=23817>

⁷⁵ This is an area of some confusion when disagreements reach the courts. There are reported cases in which courts have determined that a living will, even if several years old, represented the wishes of the patient. See, Nachman D. Living Wills: Is it Time to Pull the Plug? 18 *Elder L J* 289 (2011) (discusses the Pinette case from Florida and *In re Livadas* from New York). There are other instances in which courts have found that a health care agent can override previously expressed wishes. *SI v. RS*, 24 Misc3d 567 (Sup Ct, Nassau Co., NY, 2009). In New York, NYS Dept of Health guidance states that the health care agent's decisions, as long as they made in "good faith in light of available medical information and circumstances," should be respected, at p. 17, at https://www.health.ny.gov/regulations/task_force/reports_publications/docs/the_health_care_proxy_law_guidebook.pdf However, there is at least one case in which a court rejected a hospital's claim of good faith immunity because it followed the directions of a surrogate that were contrary to the known wishes of the patient. *Cardoza v. USC Univ Hospital*, 2008 WL 3413312 (California, Court of Appeal, Second District, Division 8, 2008).

APPENDIX – EXAMPLES OF DIFFICULT ETHICS CONSULTS

I. EXAMPLES OF DIFFICULT CONSULTS.

1. **Patient has questionable capacity and is refusing a lifesaving treatment.** Ethically, there is a primary goal to respect patient autonomy. However, in this case that could conflict with the principle of beneficence/parens patriae which requires that doctors act in the best interest of patients who lack decision-making capacity.

If a patient is objecting to treatment and lacks decision-making capacity, in New York a court order is ordinarily required (even if the patient's surrogate has consented). FYI, one exception is when the patient has a court-appointed guardian – if the guardian has the power to make health care treatment decisions, you should be able to look to the guardian to consent to medical treatment (not psychiatric treatment) without the need for a court order.

See, FHCDA PHL 2994-a (5) – definition of “decision-making capacity.”

See, PHL 2980 (3) for definition of “capacity to make health care decisions”

ALTERNATE EXAMPLE. A patient did not complete treatment for cervical cancer several months ago and left Against Medical Advice (AMA). While at home a few month later, she wakes up a few months and cannot move her legs. What is it? She needs an MRI and other testing to determine what it is going on. However, she won't agree to testing. This needs to be resolved quickly – the medical team must get to the root of the problem quickly or this could become a permanent condition.

Is she making a reasoned decision? Or does she lack insight into her condition?

Many other examples – patients refusing dialysis, patient with Substance Use Disorder Syndrome (SUDS) refusing steroid treatment for eye condition that could lead to blindness.

2. **The patient's surrogate wants “everything done”** but everything beneficial has been done and any further treatment would, in the medical team's view, cause needless suffering without little potential for recovery. This scenario is less difficult ethically if the patient expressed wishes about when and whether they want treatment in a MOLST or Living Will.

A. **EXAMPLE.** Patient MA signed a HCP 25 years ago – “I do not want artificial nutrition and hydration (feeding tubes).” She is now 88 years old and in the

hospital with either a brain tumor or CNS lymphoma. In order to rule one or the other out, a biopsy would need to be performed. However, she is too ill for that. She is mostly too sick to have capacity. She is undergoing a grueling 8-week course of palliative radiation to see if that can improve her symptoms. She is not eating and her HCP/daughter wants her to have a feeding tube.

- B. **ALTERNATE EXAMPLE.** Patient MJ is 80, widowed, adult daughter is his surrogate decision maker under the Family Health Care Decisions Act. He signed a MOLST form on a prior hospital visit a few months ago saying that he wants to be DNR/DNI. Has numerous chronic problems – congestive heart failure, kidney disease, etc. He is now in the hospital because of a one-car accident two blocks from home. Multiple emergency surgeries during this hospitalization – several orthopedic surgeries, several abdominal surgeries to stop bleeding. He has not awakened. Per MOLST from earlier visit – no tubes, DNR, comfort care. HCP agent and other adult daughter will not agree to comfort care. Other children (3) don't want to be involved. There is a lot of family trauma – Mom passed away last year, Dad/patient was abusive. Medical team has nothing more to offer.
3. **The patient's HCP agent requests a course of treatment that is harmful to the patient or where the patient has the potential for a significant recovery.**

Question: Does this constitute a lack of good faith by the agent? Would it matter if the patient told emergency personnel to “do what you need to do” when asked for consent to being intubated?

- A. **EXAMPLE** – Patient suffers recoverable burns. In ICU and is temporarily on a breathing tube. HCP form provides no directions. Daughter/HCP says stop everything. Father consented to intubation by ambulance crew and told them – “do what you need to do.”

Note: The conflicting ethical principles include whether the HCP can override the patient's expressed wishes and whether physician moral distress over not being able to save a patient who could be saved should be weighted as a factor?

- B. **ALTERNATE EXAMPLE.** See, “Make Your Wishes Known” article in The Atlantic, at <https://www.theatlantic.com/health/archive/2013/07/make-your-wishes-known/277654/>
- C. **SECOND ALTERNATE EXAMPLE.** See, Ken Prager, MD, “Must We Always Obey Health Care Proxies?” YouTube, 2018, at https://www.youtube.com/watch?v=oJw_I_DrpSw

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D. THIRD ALTERNATE EXAMPLE. 85-year-old man with moderate/severe dementia breaks ankle. A bad break – bone is sticking out. Needs surgery. His HCP/daughter says no – wrap the wound as best as you can and discharge him to my care. He told me that he never wants surgery. What do you do? Note: Get into the safe discharge category.

4. **What should be done when the advance directive appears at odds with the requests of the HCP agent. Example: SI v. RS case.** Patient has many commodities and is in the hospital but not terminally ill or permanently unconscious. Named wife as is HCP. Also said “I want to live” as his direction in the HCP. Wife has agreed to DNR and DNI. Patient’s siblings object. They argue that he is Jewish and, based on his upbringing, would want everything done. And they argue that he said so in his HCP.⁷⁶

⁷⁶ SI v. RS, 24 Misc2d 567 (NY Sup. Ct., Nassau Co., Karen V. Murphy, JSC, 2009), at <https://casetext.com/case/si-v-rs>