2017 Aging Law Series

Using Advanced Directives to Avoid Prolonged Dementia

June 6, 2017
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Using Advanced Directives to Avoid Prolonged Dementia

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Agenda

3:30pm – 4:00pm  Registration

4:00pm – 4:30pm  Overview of Legal Framework for End-of-Life Decisions
                  Lawrence R. Faulkner, Esq.

4:30pm – 5:00pm  Using Advanced Directives to Avoid Prolonged Dementia: The Clinical Reality
                  Judith K. Schwarz, PhD, RN

5:00pm – 5:30pm  Alzheimer's Disease and Advance Directives: Bringing the Conceptual Confusion Into Clinical Focus
                  Wayne Shelton, PhD.

5:30pm – 6:00pm  Changing the Paradigm of Advanced Directives to Avoid Prolonged Dementia
                  Professor Norman L. Cantor
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                 Professor Norman L. Cantor
SPEAKER BIOGRAPHIES

PROF. NORMAN CANTOR is Distinguished Professor of Law Emeritus and Nathan Jacobs Scholar Emeritus at Rutgers University School of Law, Newark. He taught in the fields of Constitutional Law, Contracts, and Bioethics (Death, Dying, and the Law). Professor Cantor has been widely published in legal and medical journals on the topic of the legal handling of dying medical patients. His four books are: After We Die: The Life and Times of the Human Cadaver (2010); Making Medical Decisions for the Profoundly Mentally Disabled (2005); Advance Directives and the Pursuit of Death with Dignity (1993); and Legal Frontiers of Death and Dying (1986). You can access several of his papers at: https://ssrn.com/author=206190. Professor Cantor is a cum laude graduate of Princeton University and a magna cum laude graduate of Columbia Law School, where he served as Notes and Comments Editor of the Columbia Law Review. He has served as a visiting professor at Columbia University, Seton Hall University, Hebrew University of Jerusalem, and Tel Aviv University. His blog is http://seekingfairness.wordpress.com.

LAWRENCE R. FAULKNER, ESQ., is the General Counsel and Director of Corporate Compliance at ARC of Westchester. In that capacity he provides general legal advice to a large not-for-profit agency and supervises the agency’s compliance program. In addition, he provides legal and legislative advocacy for the agency and those it serves, coordinates special efforts concerning emerging issues, and provides training to agency staff. Mr. Faulkner has provided educational programs for families and attorneys in such areas as health care decision making, guardianship, end of life care decision making, and family access to investigation records. He is Chair of the New York State Bar Association Health Law Section and a member of the Committee on Ethical Issues in the Provision of Health Care. He is also a member of the Committee on Disability Rights. Mr. Faulkner was instrumental in the drafting and passage of the New York Health Care Decisions Act for Persons with Intellectual and Developmental Disabilities which gives the guardians of individuals with intellectual and developmental disabilities the authority to make health care decisions, and guardians and family members the authority to make health care decisions concerned with end of life care. Mr. Faulkner has been actively involved for more than twenty years in efforts to reform guardianship in New York State, most recently as a member of the Governor’s Olmstead Task Force on reform of guardianship and a sub-committee on Supportive Decision Making. Mr. Faulkner has a BS from Cornell University and an MS and JD from the State University of New York at Buffalo. Before coming to ARC of Westchester, he served as Deputy
General Counsel at the New York State Office for People with Developmental Disabilities.

JUDITH SCHWARZ, PhD, RN, is the Clinical Director of End of Life Choices New York, and she was the East Coast Regional Clinical Coordinator for Compassion & Choices and for Compassion & Choices of NY. In that role for over a decade, she has counseled many hundreds of patients suffering from incurable and progressive or terminal illnesses and their families about end of life options and choices. She earned a PhD in nursing at New York University, where her research explored nurses’ experiences when asked by decisionally capable patients for assistance in dying. Ms. Schwarz completed an MSN at Lehman College, and a certification program in bioethics and the medical humanities at Columbia University. She has taught ethics and health care law to nursing students, lectures frequently to professional nursing and palliative care audiences as well as to lay groups, and publishes regularly in professional journals. Ms. Schwarz has recently focused her writing and speaking on the option of voluntarily stopping eating and drinking as a means to achieve a peaceful, patient-controlled dying. She has recently begun helping New Yorkers diagnosed with an early stage of dementia to complete a comprehensive written directive that stipulates refusal of assisted oral feeding once capacity and the ability to feed oneself are lost.

WAYNE SHELTON, PhD, is Professor of Medicine and Bioethics in the Alden March Bioethics Institute of Albany Medical College. After receiving a PhD from the University of Tennessee in philosophy and medical ethics, he then taught ethics and political philosophy at the university level. To become more clinically oriented, he completed an MSW with a concentration in health administration and policy and a fellowship in clinical medical ethics in the Maclean Center for Clinical Medical Ethics at the University of Chicago. Since arriving at Albany Medical College in 1994, Dr. Shelton has authored or co-authored academic articles in leading journals and edited three books on a range of topics, including medical futility, organ transplantation, and the physician-patient relationship. He was the Principal Investigator of a three-year research study in the Surgical Intensive Care Unit at Albany Medical Center, which focused on how to improve communication with stressed families at risk for conflict.
Health Care Proxy

Appointing Your Health Care Agent in New York State

The New York Health Care Proxy Law allows you to appoint someone you trust — for example, a family member or close friend — to make health care decisions for you if you lose the ability to make decisions yourself. By appointing a health care agent, you can make sure that health care providers follow your wishes. Your agent can also decide how your wishes apply as your medical condition changes. Hospitals, doctors and other health care providers must follow your agent’s decisions as if they were your own. You may give the person you select as your health care agent as little or as much authority as you want. You may allow your agent to make all health care decisions or only certain ones. You may also give your agent instructions that he or she has to follow. This form can also be used to document your wishes or instructions with regard to organ and/or tissue donation.
About the Health Care Proxy Form

This is an important legal document. Before signing, you should understand the following facts:

1. This form gives the person you choose as your agent the authority to make all health care decisions for you, including the decision to remove or provide life-sustaining treatment, unless you say otherwise in this form. “Health care” means any treatment, service or procedure to diagnose or treat your physical or mental condition.

2. Unless your agent reasonably knows your wishes about artificial nutrition and hydration (nourishment and water provided by a feeding tube or intravenous line), he or she will not be allowed to refuse or consent to those measures for you.

3. Your agent will start making decisions for you when your doctor determines that you are not able to make health care decisions for yourself.

4. You may write on this form examples of the types of treatments that you would not desire and/or those treatments that you want to make sure you receive. The instructions may be used to limit the decision-making power of the agent. Your agent must follow your instructions when making decisions for you.

5. You do not need a lawyer to fill out this form.

6. You may choose any adult (18 years of age or older), including a family member or close friend, to be your agent. If you select a doctor as your agent, he or she will have to choose between acting as your agent or as your attending doctor because a doctor cannot do both at the same time. Also, if you are a patient or resident of a hospital, nursing home or mental hygiene facility, there are special restrictions about naming someone who works for that facility as your agent. Ask staff at the facility to explain those restrictions.

7. Before appointing someone as your health care agent, discuss it with him or her to make sure that he or she is willing to act as your agent. Tell the person you choose that he or she will be your health care agent. Discuss your health care wishes and this form with your agent. Be sure to give him or her a signed copy. Your agent cannot be sued for health care decisions made in good faith.

8. If you have named your spouse as your health care agent and you later become divorced or legally separated, your former spouse can no longer be your agent by law, unless you state otherwise. If you would like your former spouse to remain your agent, you may note this on your current form and date it or complete a new form naming your former spouse.

9. Even though you have signed this form, you have the right to make health care decisions for yourself as long as you are able to do so, and treatment cannot be given to you or stopped if you object, nor will your agent have any power to object.

10. You may cancel the authority given to your agent by telling him or her or your health care provider orally or in writing.

11. Appointing a health care agent is voluntary. No one can require you to appoint one.

12. You may express your wishes or instructions regarding organ and/or tissue donation on this form.
Frequently Asked Questions

**Why should I choose a health care agent?**
If you become unable, even temporarily, to make health care decisions, someone else must decide for you. Health care providers often look to family members for guidance. Family members may express what they think your wishes are related to a particular treatment. Appointing an agent lets you control your medical treatment by:

- allowing your agent to make health care decisions on your behalf as you would want them decided;
- choosing one person to make health care decisions because you think that person would make the best decisions;
- choosing one person to avoid conflict or confusion among family members and/or significant others.

You may also appoint an alternate agent to take over if your first choice cannot make decisions for you.

**Who can be a health care agent?**
Anyone 18 years of age or older can be a health care agent. The person you are appointing as your agent or your alternate agent cannot sign as a witness on your Health Care Proxy form.

**How do I appoint a health care agent?**
All competent adults, 18 years of age or older, can appoint a health care agent by signing a form called a Health Care Proxy. You don’t need a lawyer or a notary, just two adult witnesses. Your agent cannot sign as a witness. You can use the form printed here, but you don’t have to use this form.

**When would my health care agent begin to make health care decisions for me?**
Your health care agent would begin to make health care decisions after your doctor decides that you are not able to make your own health care decisions. As long as you are able to make health care decisions for yourself, you will have the right to do so.

**What decisions can my health care agent make?**
Unless you limit your health care agent’s authority, your agent will be able to make any health care decision that you could have made if you were able to decide for yourself. Your agent can agree that you should receive treatment, choose among different treatments and decide that treatments should not be provided, in accordance with your wishes and interests. However, your agent can only make decisions about artificial nutrition and hydration (nourishment and water provided by feeding tube or intravenous line) if he or she knows your wishes from what you have said or what you have written. The Health Care Proxy form does not give your agent the power to make non-health care decisions for you, such as financial decisions.

**Why do I need to appoint a health care agent if I’m young and healthy?**
Appointing a health care agent is a good idea even though you are not elderly or terminally ill. A health care agent can act on your behalf if you become even temporarily unable to make your own health care decisions (such as might occur if you are under general anesthesia or have become comatose because of an accident). When you again become able to make your own health care decisions, your health care agent will no longer be authorized to act.

**How will my health care agent make decisions?**
Your agent must follow your wishes, as well as your moral and religious beliefs. You may write instructions on your Health Care Proxy form or simply discuss them with your agent.

**How will my health care agent know my wishes?**
Having an open and frank discussion about your wishes with your health care agent will put him or her in a better position to serve your interests. If your agent does not know your wishes or beliefs, your agent is legally required to act in your best interest. Because this is a major responsibility for the person you appoint as your health care
Frequently Asked Questions, continued

agent, you should have a discussion with the person about what types of treatments you would or would not want under different types of circumstances, such as:

- whether you would want life support initiated/continued/removed if you are in a permanent coma;
- whether you would want treatments initiated/continued/removed if you have a terminal illness;
- whether you would want artificial nutrition and hydration initiated/withheld or continued or withdrawn and under what types of circumstances.

Can my health care agent overrule my wishes or prior treatment instructions?

No. Your agent is obligated to make decisions based on your wishes. If you clearly expressed particular wishes, or gave particular treatment instructions, your agent has a duty to follow those wishes or instructions unless he or she has a good faith basis for believing that your wishes changed or do not apply to the circumstances.

Who will pay attention to my agent?

All hospitals, nursing homes, doctors and other health care providers are legally required to provide your health care agent with the same information that would be provided to you and to honor the decisions by your agent as if they were made by you. If a hospital or nursing home objects to some treatment options (such as removing certain treatment) they must tell you or your agent BEFORE or upon admission, if reasonably possible.

What if my health care agent is not available when decisions must be made?

You may appoint an alternate agent to decide for you if your health care agent is unavailable, unable or unwilling to act when decisions must be made. Otherwise, health care providers will make health care decisions for you that follow instructions you gave while you were still able to do so. Any instructions that you write on your Health Care Proxy form will guide health care providers under these circumstances.

What if I change my mind?

It is easy to cancel your Health Care Proxy, to change the person you have chosen as your health care agent or to change any instructions or limitations you have included on the form. Simply fill out a new form. In addition, you may indicate that your Health Care Proxy expires on a specified date or if certain events occur. Otherwise, the Health Care Proxy will be valid indefinitely. If you choose your spouse as your health care agent or as your alternate, and you get divorced or legally separated, the appointment is automatically cancelled. However, if you would like your former spouse to remain your agent, you may note this on your current form and date it or complete a new form naming your former spouse.

Can my health care agent be legally liable for decisions made on my behalf?

No. Your health care agent will not be liable for health care decisions made in good faith on your behalf. Also, he or she cannot be held liable for costs of your care, just because he or she is your agent.

Is a Health Care Proxy the same as a living will?

No. A living will is a document that provides specific instructions about health care decisions. You may put such instructions on your Health Care Proxy form. The Health Care Proxy allows you to choose someone you trust to make health care decisions on your behalf. Unlike a living will, a Health Care Proxy does not require that you know in advance all the decisions that may arise. Instead, your health care agent can interpret your wishes as medical circumstances change and can make decisions you could not have known would have to be made.

Where should I keep my Health Care Proxy form after it is signed?

Give a copy to your agent, your doctor, your attorney and any other family members or close friends you want. Keep a copy in your wallet or purse or with other important papers, but not in a location where no one can access it, like a safe
Can my health care agent make decisions for me about organ and/or tissue donation?
Yes. As of August 26, 2009, your health care agent is authorized to make decisions after your death, but only those regarding organ and/or tissue donation. Your health care agent must make such decisions as noted on your Health Care Proxy form.

Who can consent to a donation if I choose not to state my wishes at this time?
It is important to note your wishes about organ and/or tissue donation to your health care agent, the person designated as your decedent's agent, if one has been appointed, and your family members. New York Law provides a list of individuals who are authorized to consent to organ and/or tissue donation on your behalf. They are listed in order of priority: your health care agent; your decedent's agent; your spouse, if you are not legally separated, or your domestic partner; a son or daughter 18 years of age or older; either of your parents; a brother or sister 18 years of age or older; or a guardian appointed by a court prior to the donor's death.

May I use the Health Care Proxy form to express my wishes about organ and/or tissue donation?
Yes. Use the optional organ and tissue donation section on the Health Care Proxy form and be sure to have the section witnessed by two people. You may specify that your organs and/or tissues be used for transplantation, research or educational purposes. Any limitation(s) associated with your wishes should be noted in this section of the proxy. Failure to include your wishes and instructions on your Health Care Proxy form will not be taken to mean that you do not want to be an organ and/or tissue donor.
Health Care Proxy Form Instructions

Item (1)
Write the name, home address and telephone number of the person you are selecting as your agent.

Item (2)
If you want to appoint an alternate agent, write the name, home address and telephone number of the person you are selecting as your alternate agent.

Item (3)
Your Health Care Proxy will remain valid indefinitely unless you set an expiration date or condition for its expiration. This section is optional and should be filled in only if you want your Health Care Proxy to expire.

Item (4)
If you have special instructions for your agent, write them here. Also, if you wish to limit your agent's authority in any way, you may say so here or discuss them with your health care agent. If you do not state any limitations, your agent will be allowed to make all health care decisions that you could have made, including the decision to consent to or refuse life-sustaining treatment.

If you want to give your agent broad authority, you may do so right on the form. Simply write: I have discussed my wishes with my health care agent and alternate and they know my wishes including those about artificial nutrition and hydration.

If you wish to make more specific instructions, you could say:

If I become terminally ill, I do/don't want to receive the following types of treatments:

If I am in a coma or have little conscious understanding, with no hope of recovery, then I do/don't want the following types of treatments:

If I have brain damage or a brain disease that makes me unable to recognize people or speak and there is no hope that my condition will improve, I do/don't want the following types of treatments:

Item (5)
I have discussed with my agent my wishes about ____________ and I want my agent to make all decisions about these measures.

Examples of medical treatments about which you may wish to give your agent special instructions are listed below. This is not a complete list:

- artificial respiration
- artificial nutrition and hydration (nourishment and water provided by feeding tube)
- cardiopulmonary resuscitation (CPR)
- antipsychotic medication
- electric shock therapy
- antibiotics
- surgical procedures
- dialysis
- transplantation
- blood transfusions
- abortion
- sterilization

Item (6)
You must date and sign this Health Care Proxy form. If you are unable to sign yourself, you may direct someone else to sign in your presence. Be sure to include your address.

Item (7)
You may state wishes or instructions about organ and/or tissue donation on this form. New York law does provide for certain individuals in order of priority to consent to an organ and/or tissue donation on your behalf: your health care agent, your decedent's agent, your spouse, if you are not legally separated, or your domestic partner, a son or daughter 18 years of age or older, either of your parents, a brother or sister 18 years of age or older, a guardian appointed by a court prior to the donor's death.

Item (8)
Two witnesses 18 years of age or older must sign this Health Care Proxy form. The person who is appointed your agent or alternate agent cannot sign as a witness.
Health Care Proxy

(1) I, ____________________________________________

hereby appoint __________________________

(name, home address and telephone number)

________________________________________

as my health care agent to make any and all health care decisions for me, except to the extent that I
state otherwise. This proxy shall take effect only when and if I become unable to make my own health
care decisions.

(2) Optional: Alternate Agent

If the person I appoint is unable, unwilling or unavailable to act as my health care agent, I hereby

appoint __________________________

(name, home address and telephone number)

________________________________________

as my health care agent to make any and all health care decisions for me, except to the extent that I
state otherwise.

(3) Unless I revoke it or state an expiration date or circumstances under which it will expire, this proxy shall
remain in effect indefinitely. (Optional: If you want this proxy to expire, state the date or conditions
here.) This proxy shall expire (specify date or conditions): __________________________

________________________________________

(4) Optional: I direct my health care agent to make health care decisions according to my wishes and
limitations, as he or she knows or as stated below. (If you want to limit your agent’s authority to make
health care decisions for you or to give specific instructions, you may state your wishes or limitations
here.) I direct my health care agent to make health care decisions in accordance with the following
limitations and/or instructions (attach additional pages as necessary): __________________________

________________________________________

In order for your agent to make health care decisions for you about artificial nutrition and hydration
(nourishment and water provided by feeding tube and intravenous line), your agent must reasonably
know your wishes. You can either tell your agent what your wishes are or include them in this section.
See instructions for sample language that you could use if you choose to include your wishes on this
form, including your wishes about artificial nutrition and hydration.
(5) **Your Identification (please print)**

Your Name ____________________________________________

Your Signature ____________________________ Date __________________

Your Address _____________________________________________

(6) **Optional: Organ and/or Tissue Donation**

I hereby make an anatomical gift, to be effective upon my death, of:
(check any that apply)

☐ Any needed organs and/or tissues

☐ The following organs and/or tissues ____________________________________

☐ Limitations _____________________________________________

If you do not state your wishes or instructions about organ and/or tissue donation on this form, it will not be taken to mean that you do not wish to make a donation or prevent a person, who is otherwise authorized by law, to consent to a donation on your behalf.

Your Signature ____________________________ Date __________________

(7) **Statement by Witnesses** *(Witnesses must be 18 years of age or older and cannot be the health care agent or alternate.)*

I declare that the person who signed this document is personally known to me and appears to be of sound mind and acting of his or her own free will. He or she signed (or asked another to sign for him or her) this document in my presence.

Date ____________________________ Date ____________________________

Name of Witness 1 (print) ____________________________________________

Name of Witness 2 (print) ____________________________________________

Signature ____________________________________________ Signature ____________________________________________

Address ____________________________________________ Address ____________________________________________
Relevant Statutes

New York Public Health Law § 2982: Rights and Duties of an agent appointed pursuant to a health care proxy

1. Scope of authority. Subject to any express limitations in the health care proxy, an agent shall have the authority to make any and all health care decisions on the principal's behalf that the principal could make. Such authority shall be subject to the provisions of section twenty-nine hundred eighty-nine of this article.

2. Decision-making standard. After consultation with a licensed physician, registered nurse, licensed psychologist, licensed master social worker, or a licensed clinical social worker, the agent shall make health care decisions: (a) in accordance with the principal's wishes, including the principal's religious and moral beliefs; or (b) if the principal's wishes are not reasonably known and cannot with reasonable diligence be ascertained, in accordance with the principal's best interests; provided, however, that if the principal's wishes regarding the administration of artificial nutrition and hydration are not reasonably known and cannot with reasonable diligence be ascertained, the agent shall not have the authority to make decisions regarding these measures.

3. Right to receive information. Notwithstanding any law to the contrary, the agent shall have the right to receive medical information and medical and clinical records necessary to make informed decisions regarding the principal's health care.

4. Priority over other surrogates. Health care decisions by an agent on a principal's behalf pursuant to this article shall have priority over decisions by any other person, except as otherwise provided in the health care proxy or in subdivision five of section two thousand nine hundred eighty-three of this article.
New York Public Health Law § 2994-d: Health care decisions for adult patients by surrogates

1. Identifying the surrogate. One person from the following list from the class highest in priority when persons in prior classes are not reasonably available, willing, and competent to act, shall be the surrogate for an adult patient who lacks decision-making capacity. However, such person may designate any other person on the list to be surrogate, provided no one in a class higher in priority than the person designated objects:
   (a) A guardian authorized to decide about health care pursuant to article eighty-one of the mental hygiene law;
   (b) The spouse, if not legally separated from the patient, or the domestic partner;
   (c) A son or daughter eighteen years of age or older;
   (d) A parent;
   (e) A brother or sister eighteen years of age or older;
   (f) A close friend.

2. Restrictions on who may be a surrogate. An operator, administrator, or employee of a hospital or a mental hygiene facility from which the patient was transferred, or a physician who has privileges at the hospital or a health care provider under contract with the hospital may not serve as the surrogate for any adult who is a patient of such hospital, unless such individual is related to the patient by blood, marriage, domestic partnership, or adoption, or is a close friend of the patient whose friendship with the patient preceded the patient's admission to the facility. If a physician serves as surrogate, the physician shall not act as the patient's attending physician after his or her authority as surrogate begins.

3. Authority and duties of surrogate. (a) Scope of surrogate's authority.
   (i) Subject to the standards and limitations of this article, the surrogate shall have the authority to make any and all health care decisions on the adult patient's behalf that the patient could make.
   (ii) Nothing in this article shall obligate health care providers to seek the consent of a surrogate if an adult patient has already made a decision about the proposed health care, expressed orally or in writing or, with respect to a decision to withdraw or withhold life-sustaining treatment expressed either orally during hospitalization in the presence of two witnesses eighteen years of age or older, at least one of whom is a health or social services practitioner affiliated with the hospital, or in writing. If an attending physician relies on the patient's prior decision, the physician shall record the prior decision in the patient's medical record. If a surrogate has already been designated for the patient, the attending physician shall make reasonable efforts to notify the surrogate prior to implementing the decision; provided that in the case of a decision to withdraw or withhold life-sustaining treatment, the attending physician shall make diligent efforts to notify the surrogate and, if unable to notify the surrogate, shall document the efforts that were made to do so.
   (b) Commencement of surrogate's authority. The surrogate's authority shall commence upon a determination, made pursuant to section twenty-nine hundred ninety-four-c of this article, that the adult patient lacks decision-making capacity and upon identification of a surrogate pursuant
to subdivision one of this section. In the event an attending physician determines that the patient has regained decision-making capacity, the authority of the surrogate shall cease.

(c) Right and duty to be informed. Notwithstanding any law to the contrary, the surrogate shall have the right to receive medical information and medical records necessary to make informed decisions about the patient's health care. Health care providers shall provide and the surrogate shall seek information necessary to make an informed decision, including information about the patient's diagnosis, prognosis, the nature and consequences of proposed health care, and the benefits and risks of and alternative to proposed health care.

4. Decision-making standards. (a) The surrogate shall make health care decisions:
(i) in accordance with the patient's wishes, including the patient's religious and moral beliefs; or
(ii) if the patient's wishes are not reasonably known and cannot with reasonable diligence be ascertained, in accordance with the patient's best interests. An assessment of the patient's best interests shall include: consideration of the dignity and uniqueness of every person; the possibility and extent of preserving the patient's life; the preservation, improvement or restoration of the patient's health or functioning; the relief of the patient's suffering; and any medical condition and such other concerns and values as a reasonable person in the patient's circumstances would wish to consider.

(b) In all cases, the surrogate's assessment of the patient's wishes and best interests shall be patient-centered; health care decisions shall be made on an individualized basis for each patient, and shall be consistent with the values of the patient, including the patient's religious and moral beliefs, to the extent reasonably possible.

5. Decisions to withhold or withdraw life-sustaining treatment. In addition to the standards set forth in subdivision four of this section, decisions by surrogates to withhold or withdraw life-sustaining treatment (including decisions to accept a hospice plan of care that provides for the withdrawal or withholding of life-sustaining treatment) shall be authorized only if the following conditions are satisfied, as applicable:

(a)(i) Treatment would be an extraordinary burden to the patient and an attending physician determines, with the independent concurrence of another physician, that, to a reasonable degree of medical certainty and in accord with accepted medical standards, (A) the patient has an illness or injury which can be expected to cause death within six months, whether or not treatment is provided; or (B) the patient is permanently unconscious; or

(ii) The provision of treatment would involve such pain, suffering or other burden that it would reasonably be deemed inhumane or extraordinarily burdensome under the circumstances and the patient has an irreversible or incurable condition, as determined by an attending physician with the independent concurrence of another physician to a reasonable degree of medical certainty and in accord with accepted medical standards.

(b) In a residential health care facility, a surrogate shall have the authority to refuse life-sustaining treatment under subparagraph (ii) of paragraph (a) of this subdivision only if the ethics review committee, including at least one physician who is not directly responsible for the patient's care, or a court of competent jurisdiction, reviews the decision and determines that it meets the standards set forth in this article. This requirement shall not apply to a decision to withhold cardiopulmonary resuscitation.

(c) In a general hospital, if the attending physician objects to a surrogate's decision, under subparagraph (ii) of paragraph (a) of this subdivision, to withdraw or withhold nutrition and hydration provided by means of medical treatment, the decision shall not be implemented until
the ethics review committee, including at least one physician who is not directly responsible for
the patient's care, or a court of competent jurisdiction, reviews the decision and determines that it
meets the standards set forth in this subdivision and subdivision four of this section.
(d) Providing nutrition and hydration orally, without reliance on medical treatment, is not health
care under this article and is not subject to this article.
(e) Expression of decisions. The surrogate shall express a decision to withdraw or withhold life-
sustaining treatment either orally to an attending physician or in writing.
New York Surrogate's Court Procedure Act § 1750-b. Health care decisions for persons who are intellectually disabled

1. Scope of authority. Unless specifically prohibited by the court after consideration of the determination, if any, regarding a person who is intellectually disabled's capacity to make health care decisions, which is required by section seventeen hundred fifty of this article, the guardian of such person appointed pursuant to section seventeen hundred fifty of this article shall have the authority to make any and all health care decisions, as defined by subdivision six of section twenty-nine hundred eighty of the public health law, on behalf of the person who is intellectually disabled that such person could make if such person had capacity. Such decisions may include decisions to withhold or withdraw life-sustaining treatment. For purposes of this section, "life-sustaining treatment" means medical treatment, including cardiopulmonary resuscitation and nutrition and hydration provided by means of medical treatment, which is sustaining life functions and without which, according to reasonable medical judgment, the patient will die within a relatively short time period. Cardiopulmonary resuscitation is presumed to be life-sustaining treatment without the necessity of a medical judgment by an attending physician. The provisions of this article are not intended to permit or promote suicide, assisted suicide or euthanasia; accordingly, nothing in this section shall be construed to permit a guardian to consent to any act or omission to which the person who is intellectually disabled could not consent if such person had capacity.

(a) For the purposes of making a decision to withhold or withdraw life-sustaining treatment pursuant to this section, in the case of a person for whom no guardian has been appointed pursuant to section seventeen hundred fifty or seventeen hundred fifty-a of this article, a "guardian" shall also mean a family member of a person who (i) has intellectual disability, or (ii) has a developmental disability, as defined in section 1.03 of the mental hygiene law, which (A) includes intellectual disability, or (B) results in a similar impairment of general intellectual functioning or adaptive behavior so that such person is incapable of managing himself or herself, and/or his or her affairs by reason of such developmental disability. Qualified family members shall be included in a prioritized list of said family members pursuant to regulations established by the commissioner of the office for people with developmental disabilities. Such family members must have a significant and ongoing involvement in a person's life so as to have sufficient knowledge of their needs and, when reasonably known or ascertainable, the person's wishes, including moral and religious beliefs. In the case of a person who was a resident of the former Willowbrook state school on March seventeenth, nineteen hundred seventy-two and those individuals who were in community care status on that date and subsequently returned to Willowbrook or a related facility, who are fully represented by the consumer advisory board and who have no guardians appointed pursuant to this article or have no qualified family members to make such a decision, then a "guardian" shall also mean the Willowbrook consumer advisory board. A decision of such family member or the Willowbrook consumer advisory board to withhold or withdraw life-sustaining treatment shall be subject to all of the protections, procedures and safeguards which apply to the decision of a guardian to withhold or withdraw life-sustaining treatment pursuant to this section.

In the case of a person for whom no guardian has been appointed pursuant to this article or for whom there is no qualified family member or the Willowbrook consumer advisory board available to make such a decision, a "guardian" shall also mean, notwithstanding the definitions in section 80.03 of the mental hygiene law, a surrogate decision-making committee, as defined in article eighty of the mental hygiene law. All declarations and procedures, including expedited
procedures, to comply with this section shall be established by regulations promulgated by the commission on quality of care and advocacy for persons with disabilities.

(b) Regulations establishing the prioritized list of qualified family members required by paragraph (a) of this subdivision shall be developed by the commissioner of the office for people with developmental disabilities in conjunction with parents, advocates and family members of persons who are intellectually disabled. Regulations to implement the authority of the Willowbrook consumer advisory board pursuant to paragraph (a) of this subdivision may be promulgated by the commissioner of the office for people with developmental disabilities with advice from the Willowbrook consumer advisory board.

(c) Notwithstanding any provision of law to the contrary, the formal determinations required pursuant to section seventeen hundred fifty of this article shall only apply to guardians appointed pursuant to section seventeen hundred fifty or seventeen hundred fifty-a of this article.

2. Decision-making standard. (a) The guardian shall base all advocacy and health care decision-making solely and exclusively on the best interests of the person who is intellectually disabled and, when reasonably known or ascertainable with reasonable diligence, on the person who is intellectually disabled's wishes, including moral and religious beliefs.

(b) An assessment of the person who is intellectually disabled's best interests shall include consideration of:

(i) the dignity and uniqueness of every person;

(ii) the preservation, improvement or restoration of the person who is intellectually disabled's health;

(iii) the relief of the person who is intellectually disabled's suffering by means of palliative care and pain management;

(iv) the unique nature of artificially provided nutrition or hydration, and the effect it may have on the person who is intellectually disabled; and

(v) the entire medical condition of the person.

(c) No health care decision shall be influenced in any way by:

(i) a presumption that persons who are intellectually disabled are not entitled to the full and equal rights, equal protection, respect, medical care and dignity afforded to persons without an intellectual disability or a developmental disability; or

(ii) financial considerations of the guardian, as such considerations affect the guardian, a health care provider or any other party.

3. Right to receive information. Subject to the provisions of sections 33.13 and 33.16 of the mental hygiene law, the guardian shall have the right to receive all medical information and medical and clinical records necessary to make informed decisions regarding the person who is intellectually disabled's health care.

4. Life-sustaining treatment. The guardian shall have the affirmative obligation to advocate for the full and efficacious provision of health care, including life-sustaining treatment. In the event that a guardian makes a decision to withdraw or withhold life-sustaining treatment from a person who is intellectually disabled:
(a) The attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law, must confirm to a reasonable degree of medical certainty that the person who is intellectually disabled lacks capacity to make health care decisions. The determination thereof shall be included in the person who is intellectually disabled's medical record, and shall contain such attending physician's opinion regarding the cause and nature of the person who is intellectually disabled's incapacity as well as its extent and probable duration. The attending physician who makes the confirmation shall consult with another physician, or a licensed psychologist, to further confirm the person who is intellectually disabled's lack of capacity. The attending physician who makes the confirmation, or the physician or licensed psychologist with whom the attending physician consults, must (i) be employed by a developmental disabilities services office named in section 13.17 of the mental hygiene law or employed by the office for people with developmental disabilities to provide treatment and care to people with developmental disabilities, or (ii) have been employed for a minimum of two years to render care and service in a facility or program operated, licensed or authorized by the office for people with developmental disabilities, or (iii) have been approved by the commissioner of the office for people with developmental disabilities in accordance with regulations promulgated by such commissioner. Such regulations shall require that a physician or licensed psychologist possess specialized training or three years experience in treating intellectual disability. A record of such consultation shall be included in the person who is intellectually disabled's medical record.

(b) The attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law, with the concurrence of another physician with whom such attending physician shall consult, must determine to a reasonable degree of medical certainty and note on the person who is intellectually disabled's chart that:

(i) the person who is intellectually disabled has a medical condition as follows:
A. a terminal condition, as defined in subdivision twenty-three of section twenty-nine hundred sixty-one of the public health law; or
B. permanent unconsciousness; or
C. a medical condition other than such person's intellectual disability which requires life-sustaining treatment, is irreversible and which will continue indefinitely; and

(ii) the life-sustaining treatment would impose an extraordinary burden on such person, in light of:
A. such person's medical condition, other than such person's intellectual disability; and
B. the expected outcome of the life-sustaining treatment, notwithstanding such person's intellectual disability; and

(iii) in the case of a decision to withdraw or withhold artificially provided nutrition or hydration:
A. there is no reasonable hope of maintaining life; or
B. the artificially provided nutrition or hydration poses an extraordinary burden.

(c) The guardian shall express a decision to withhold or withdraw life-sustaining treatment either:
(i) in writing, dated and signed in the presence of one witness eighteen years of age or older who shall sign the decision, and presented to the attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law; or
(ii) orally, to two persons eighteen years of age or older, at least one of whom is the person who is intellectually disabled's attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law.
(d) The attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law, who is provided with the decision of a guardian shall include the decision in the person who is intellectually disabled's medical chart, and shall either:
(i) promptly issue an order to withhold or withdraw life-sustaining treatment from the person who is intellectually disabled, and inform the staff responsible for such person's care, if any, of the order; or
(ii) promptly object to such decision, in accordance with subdivision five of this section.
(e) At least forty-eight hours prior to the implementation of a decision to withdraw life-sustaining treatment, or at the earliest possible time prior to the implementation of a decision to withhold life-sustaining treatment, the attending physician shall notify:
(i) the person who is intellectually disabled, except if the attending physician determines, in writing and in consultation with another physician or a licensed psychologist, that, to a reasonable degree of medical certainty, the person would suffer immediate and severe injury from such notification. The attending physician who makes the confirmation, or the physician or licensed psychologist with whom the attending physician consults, shall:
A. be employed by a developmental disabilities services office named in section 13.17 of the mental hygiene law or employed by the office for people with developmental disabilities to provide treatment and care to people with developmental disabilities, or
B. have been employed for a minimum of two years to render care and service in a facility operated, licensed or authorized by the office for people with developmental disabilities, or
C. have been approved by the commissioner of the office for people with developmental disabilities in accordance with regulations promulgated by such commissioner. Such regulations shall require that a physician or licensed psychologist possess specialized training or three years experience in treating intellectual disability. A record of such consultation shall be included in the person who is intellectually disabled's medical record;
(ii) if the person is in or was transferred from a residential facility operated, licensed or authorized by the office for people with developmental disabilities, the chief executive officer of the agency or organization operating such facility and the mental hygiene legal service; and
(iii) if the person is not in and was not transferred from such a facility or program, the commissioner of the office for people with developmental disabilities, or his or her designee.

5. Objection to health care decision. (a) Suspension. A health care decision made pursuant to subdivision four of this section shall be suspended, pending judicial review, except if the suspension would in reasonable medical judgment be likely to result in the death of the person who is intellectually disabled, in the event of an objection to that decision at any time by:
(i) the person who is intellectually disabled on whose behalf such decision was made; or
(ii) a parent or adult sibling who either resides with or has maintained substantial and continuous contact with the person who is intellectually disabled; or
(iii) the attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law; or
(iv) any other health care practitioner providing services to the person who is intellectually disabled, who is licensed pursuant to article one hundred thirty-one, one hundred thirty-one-B, one hundred thirty-two, one hundred thirty-three, one hundred thirty-six, one hundred thirty-nine, one hundred forty-one, one hundred forty-three, one hundred forty-four, one hundred fifty-
three, one hundred fifty-four, one hundred fifty-six, one hundred fifty-nine or one hundred sixty-four of the education law; or
(v) the chief executive officer identified in subparagraph (ii) of paragraph (e) of subdivision four of this section; or
(vi) if the person is in or was transferred from a residential facility or program operated, approved or licensed by the office for people with developmental disabilities, the mental hygiene legal service; or
(vii) if the person is not in and was not transferred from such a facility or program, the commissioner of the office for people with developmental disabilities, or his or her designee.
(b) Form of objection. Such objection shall occur orally or in writing.
(c) Notification. In the event of the suspension of a health care decision pursuant to this subdivision, the objecting party shall promptly notify the guardian and the other parties identified in paragraph (a) of this subdivision, and the attending physician shall record such suspension in the person who is intellectually disabled's medical chart.
(d) Dispute mediation. In the event of an objection pursuant to this subdivision, at the request of the objecting party or person or entity authorized to act as a guardian under this section, except a surrogate decision making committee established pursuant to article eighty of the mental hygiene law, such objection shall be referred to a dispute mediation system, established pursuant to section two thousand nine hundred seventy-two of the public health law or similar entity for mediating disputes in a hospice, such as a patient's advocate's office, hospital chaplain's office or ethics committee, as described in writing and adopted by the governing authority of such hospice, for non-binding mediation. In the event that such dispute cannot be resolved within seventy-two hours or no such mediation entity exists or is reasonably available for mediation of a dispute, the objection shall proceed to judicial review pursuant to this subdivision. The party requesting mediation shall provide notification to those parties entitled to notice pursuant to paragraph (a) of this subdivision.

6. Special proceeding authorized. The guardian, the attending physician, as defined in subdivision two of section twenty-nine hundred eighty of the public health law, the chief executive officer identified in subparagraph (ii) of paragraph (e) of subdivision four of this section, the mental hygiene legal service (if the person is in or was transferred from a residential facility or program operated, approved or licensed by the office for people with developmental disabilities) or the commissioner of the office for people with developmental disabilities or his or her designee (if the person is not in and was not transferred from such a facility or program) may commence a special proceeding in a court of competent jurisdiction with respect to any dispute arising under this section, including objecting to the withdrawal or withholding of life-sustaining treatment because such withdrawal or withholding is not in accord with the criteria set forth in this section.

7. Provider's obligations. (a) A health care provider shall comply with the health care decisions made by a guardian in good faith pursuant to this section, to the same extent as if such decisions had been made by the person who is intellectually disabled, if such person had capacity.
(b) Notwithstanding paragraph (a) of this subdivision, nothing in this section shall be construed to require a private hospital to honor a guardian's health care decision that the hospital would not honor if the decision had been made by the person who is intellectually disabled, if such person had capacity, because the decision is contrary to a formally adopted written policy of the hospital expressly based on religious beliefs or sincerely held moral convictions central to the hospital's
operating principles, and the hospital would be permitted by law to refuse to honor the decision if made by such person, provided:
(i) the hospital has informed the guardian of such policy prior to or upon admission, if reasonably possible; and
(ii) the person who is intellectually disabled is transferred promptly to another hospital that is reasonably accessible under the circumstances and is willing to honor the guardian's decision. If the guardian is unable or unwilling to arrange such a transfer, the hospital's refusal to honor the decision of the guardian shall constitute an objection pursuant to subdivision five of this section.
(c) Notwithstanding paragraph (a) of this subdivision, nothing in this section shall be construed to require an individual health care provider to honor a guardian's health care decision that the individual would not honor if the decision had been made by the person who is intellectually disabled, if such person had capacity, because the decision is contrary to the individual's religious beliefs or sincerely held moral convictions, provided the individual health care provider promptly informs the guardian and the facility, if any, of his or her refusal to honor the guardian's decision. In such event, the facility shall promptly transfer responsibility for the person who is intellectually disabled to another individual health care provider willing to honor the guardian's decision. The individual health care provider shall cooperate in facilitating such transfer of the patient.
(d) Notwithstanding the provisions of any other paragraph of this subdivision, if a guardian directs the provision of life-sustaining treatment, the denial of which in reasonable medical judgment would be likely to result in the death of the person who is intellectually disabled, a hospital or individual health care provider that does not wish to provide such treatment shall nonetheless comply with the guardian's decision pending either transfer of the person who is intellectually disabled to a willing hospital or individual health care provider, or judicial review.
(e) Nothing in this section shall affect or diminish the authority of a surrogate decision-making panel to render decisions regarding major medical treatment pursuant to article eighty of the mental hygiene law.

8. Immunity. (a) Provider immunity. No health care provider or employee thereof shall be subjected to criminal or civil liability, or be deemed to have engaged in unprofessional conduct, for honoring reasonably and in good faith a health care decision by a guardian, or for other actions taken reasonably and in good faith pursuant to this section.
(b) Guardian immunity. No guardian shall be subjected to criminal or civil liability for making a health care decision reasonably and in good faith pursuant to this section.
Chapter 210 of the 2008 Laws of New York and Memorandum in Support
(see below)
LAWS OF NEW YORK, 2008

CHAPTER 210

AN ACT to amend the mental hygiene law, in relation to providing for a
simplified advance health care directives form for persons receiving
mental retardation and developmental disabilities services; and
providing for the repeal of such provisions upon expiration thereof

Became a law July 7, 2008, with the approval of the Governor.
Passed by a majority vote, three-fifths being present.

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

Section 1. Section 33.03 of the mental hygiene law is amended by adding a new subdivision (e) to read as follows:

(e) 1. Notwithstanding the provisions of subdivisions four and five of section twenty-nine hundred eighty-one of the public health law, the commissioners of health, and mental retardation and developmental disabili-
ties may approve and authorize the use of a simplified advance health care directives form by persons receiving supports and services from a provider of services which is authorized to provide services pursuant to article sixteen of this chapter. Such form shall specify, at the option of the principal, what end-of-life treatment the person wishes to receive; may designate a health care agent consistent with the provisions of this article; and may, at the option of the principal, authorize the health care agent to commence making decisions immediately upon the execution of the proxy, provided that all such decisions made prior to a determination of incapacity pursuant to section twenty-nine hundred eighty-three of the public health law shall be made in direct consultation with the principal and the attending physician; and provided, further, that if, after such consultation, the principal disagrees with the agent's proposed decision, the principal's wishes shall prevail; and provided, further, that, in the case of any decision to withhold or withdraw artificial nutrition or hydration, the principal's wishes must have been recorded in the health care directive or stated in the presence of the agent and the attending physician; and further, provided, that the consultation among principal, agent and attending physician must be summarized and recorded in the principal's medical record.

2. The simplified advance health care directives form, authorized by paragraph one of this subdivision, shall be developed by the commissioner of mental retardation and developmental disabilities, in consultation with the commissioner of health, providers of service authorized to provide services pursuant to article sixteen of this chapter, advocates, including self-advocates, and parents and family members of persons receiving services from such providers.

§ 2. Notwithstanding the provisions of section 2991 of the public health law, facilities licensed or authorized pursuant to article 16 of the mental hygiene law may utilize the simplified advance health care directives form, established pursuant to subdivision (e) of section

EXPLANATION--Matter in italics is new; matter in brackets [ ] is old law to be omitted.
33.03 of the mental hygiene law, in fulfillment of their responsibilities pursuant to such section of the public health law.

§ 3. Notwithstanding the provisions of sections 2963, 2965, 2981 and 2983 of the public health law, a health care agent appointed pursuant to subdivision (e) of section 33.03 of the mental hygiene law may make any and all decisions authorized by articles 29-B and 29-C of the public health law, regardless of the principal's capacity, provided that the principal has elected to authorize such agent and that any such decision is made in direct consultation with the principal and the attending physician.

§ 4. On or before the date of repeal of the provisions of this act, the commissioner of mental retardation and developmental disabilities, in cooperation with the commissioner of health, parents, family members, advocates, including self-advocates, and providers of services, shall submit a report to the governor and the legislature on the acceptance and usefulness of the form established pursuant to subdivision (e) of section 33.03 of the mental hygiene law.

§ 5. This act shall take effect upon the date of the approval and availability of the simplified advance health care directives form authorized by subdivision (e) of section 33.03 of the mental hygiene law, as added by section one of this act, and shall expire and be deemed repealed 2 years after such date. Provided that the commissioner of mental retardation and developmental disabilities shall notify the legislative bill drafting commission upon the day of the approval and availability of such form in order that the commission may maintain an accurate and timely effective data base of the official text of the laws of the state of New York in furtherance of effectuating the provisions of section 44 of the legislative law and section 70-b of the public officers law.

The Legislature of the STATE OF NEW YORK ss:

Pursuant to the authority vested in us by section 70-b of the Public Officers Law, we hereby jointly certify that this slip copy of this session law was printed under our direction and, in accordance with such section, is entitled to be read into evidence.

JOSEPH L. BRUNO
Temporary President of the Senate

SHELDON SILVER
Speaker of the Assembly
NEW YORK STATE ASSEMBLY
MEMORANDUM IN SUPPORT OF LEGISLATION
submitted in accordance with Assembly Rule III, Sec 1(f)

BILL NUMBER: A11054A

SPONSOR: Rivera P

TITLE OF BILL: An act to amend the mental hygiene law, in relation to providing for a simplified advance health care directives form for persons receiving mental retardation and developmental disabilities services; and providing for the repeal of such provisions upon expiration thereof

PURPOSE OF BILL: To permit a demonstration of the use of a simplified advance health care directive form, modified for New York State use from a form developed and tested in the state of California, where its use of simplified language made it significantly more user-friendly to both health care providers and patients than forms previously used in health care facilities.

SUMMARY OF PROVISIONS OF BILL: Section 1: authorizes, on an elective, demonstration basis, the use of a simplified advance health care directive form, approved and authorized by the Commissioners of Health and MRDD, in the OMRDD provider community. The form would contain, at the principal's option, specific and general instructions to providers on end-of-life care, as well as designation of a health care agent with authority to act immediately upon execution of the proxy.

Section 2: authorizes the use of the approved demo form to satisfy OMRDD providers' duties to inform and educate persons with intellectual and other developmental disabilities concerning their rights to voluntarily fill out and execute a health care proxy, as imposed by public health law section 2991.

Section 3: authorizes a health care agent appointed under the authority of the demo to exercise all the authority conferred upon a health care agent by Articles 39-B (orders not to reuscitate) and 29-C (health care agents and proxies) of the Public Health Law, without the need to determine the principal's capacity, provided the principal has so elected in the form, and provided that the principal is consulted by the agent and the attending physician in the making of the decision.

Section 4: requires the Commissioners of Health and MRDD to study and report to the legislature on the usefulness of the form and the demo.

Section 5: provides that the statute shall become effective upon the approval of the form by the Commissioners of Health and Mental Retardation and Developmental Disabilities and shall terminate two years thereafter.

EXISTING LAW: Public Health Law Article 29-C provides for the creation
of a health care proxy and presumes that every adult has capacity to execute one (absent an adjudication of incompetency). Public Health Law section 2981 provides a suggested (not mandated) form for a health care proxy; subsection 4 thereof provides that a health care agent's authority commences only upon a formal determination of the principal's lack of capacity to make health care decisions; and Public Health Law section 2983 provides that where a principal confronts a decision to withhold or withdraw life-sustaining treatment and appears to have an intellectual or other developmental disability, the process of determining incapacity requires not only an examination by the attending physician, but also a consultation and concurrence from another physician or clinical psychologist with special experience and qualifications. Other states, including California, permit the principal to invest a health care agent with immediate authority to make all health care decisions.

A principal may revoke a health care proxy at any time orally or in writing (or by any other act evincing an intention to revoke). The public health law section 2965 5. (in the case of orders not to resuscitate) and surrogate's court procedure act 1750-11 4. (e) (in the case of declination of life-sustaining treatment) both require that the patient be notified of a decision involving end-of-life treatment made by a surrogate, and that mental hygiene legal services and his residential service provider be informed in some cases, as well. Objection by a patient to such a declination of end-of-life treatment is also stayed by an objection and the matter may be reviewed in a court of competent jurisdiction.

**JUSTIFICATION:** The simplified advance health care directive form was modified from a form developed in the state of California. It uses simple Rath grade-accessible language to describe situations and choices. Together with the graphics and layout, this form was found to be vastly preferable to prior fonts among patients and health care professionals, especially with institutionalized and elderly populations. The MOLST forms, which extend significantly beyond resuscitation decisions, are not a good fit with SCPA 1750-b requirements, and MR/DD and MT populations were exempted from the prior demo. It is hoped that with the projected extension of the MOLST statute statewide, the simplified advance directives form can be utilized to augment or as an option for those persons whose capacity may be limited by intellectual or other developmental disabilities.

Virtually all persons with intellectual and other developmental disabilities are (or soon will be) served in small community-based facilities (and some in their own homes). They are entitled to the presumptions contained in statute that they enjoy the same full array of constitutional and other rights enjoyed by all - e.g., Mental Hygiene Law 33.01 "...no person shall be deprived of any civil right, if in all other respects qualified and eligible, solely by reason of receipt of services for a mental disability nor shall the receipt of such services modify or vary any civil right of any such person..."; and Public Health Law 2981 1. (a) and (b) "...a competent adult may appoint a health care agent in accordance with the terms of this article...(and)...every adult shall be presumed competent to appoint a health care agent unless such person has been adjudged incompetent...". It is frequently the case that persons served in the OMRDD system have capacity to formulate and express their wishes as to health care, and even care at the end of life; the capacity to form and maintain testing and meaningful relationships with friends, family and care-givers; and the capacity to evaluate their relationships and place trust in others.
There is no clear public policy underlying the public health law requirement that a person be determined incapacitated from making his or her own health care decisions before a health care agent's authority begins. Other states permit a principal to authorize a health care agent to act immediately. Furthermore, it is clear public policy that persons with intellectual and other developmental disabilities be granted the right to designate health care agents (Public Health Law 2981 and 14 NYCRR 633.20 (a)(20), (21) and (23)). The Commissioners of Health and Mental Retardation and Developmental Disabilities agree in interpreting the public health law to require only that a principal understand the general nature and importance of the rights being granted to the agent, conceding that at the point of execution of the proxy the principal may well already lack capacity to make many health care decisions involving complex alternatives, risks and benefits. OMRDD and DOH have also agreed and advised all hospital administrators in writing on 9/6/06 that "...a duly authorized health care agent may act where the principal lacks the capacity-to communicate a health care decision" (recognizing that it would be pointless to force a hospital to go through the burden of satisfying PHL 2983 for a person whose disability included a significant communication deficit). Nor do New York statutes confer all agent authority to times of intellectual incapacity. Public Health Law section 2964 3. (a) (iv) permits a serving physician to accept the consent of a health care agent in the situation where a patient is deemed to be susceptible to immediate and serious injury were cardiopulmonary resuscitation discussed with him or her directly.

Most providers of services to New Yorkers with intellectual and other developmental disabilities, provides lifelong 24/7 supports and services, including increasingly the opportunity to spend a persons final days in their home among people they know, trust and love. Clearly statutes like Public Health Law articles 29-B and 29-C and SCPA section 1750-b assume that people with disabilities will confront their end-of-life decisions in a hospital. These statutes assume the immediate availability of attending physicians and concuring physicians or licensed psychologists. In actuality, the average size of an OMRDD community residential facility is in the neighborhood of four beds with medical and clinical services and supports provided by community health care providers. In order to make decisions necessary for a dignified and comfortable end-of-life in such an environment it is often very time-consuming and burdensome for agency staff to comply with the statutes. This bill can be reasonably anticipated to ease that burden to an extent; to facilitate the public policy of disabled persons having access to health care proxies (the legislature's principal response to date to the court of appeals decision in Matter of O'Connor); and it is also foreseeable that the use of this form for other populations, such as nursing home and adult care facilities, will develop.

The existing statutory scheme will continue to provide systemic protections for persons with intellectual and other developmental disabilities, including: Public Health Law 2981 2. (e) which specifies that for persons served in OMRDD-operated/certified facilities at least one witness to a health care proxy must be unaffiliated with the provider and one witness must be either a physician or a licensed psychologist with special expertise in serving persons with intellectual or other developmental disabilities; Public Health Law 2981 3. (a) and 14 NYCRR 681. which prevent a class of persons directly associated with the principal's routine care from becoming his/her health care agent; and Public Health Law 2981 3. (d) which precludes a person (not directly related by blood to the principal) from being the agent for more than 10
persons. Also, Public Health Law 2905 provides that a principal may revoke a health care proxy "...orally or in writing or by any other act evidencing a specific intent to revoke the proxy." For purposes of revocation "every adult shall be presumed competent unless determined otherwise pursuant to a court order..."

Obviously the most direct protection afforded by this bill, and not by the existing statutory scheme, is that any decision to be made by the agent prior to a formal determination of the principal's incapacity, must be made in direct consultation arming the principal, the agent and the attending physician.

The report required at the close of the two year demo will reveal the usefulness of the form alongside the MOLST and other standard forms now used.

**LEGISLATIVE HISTORY:** New bill.

**FISCAL IMPLICATIONS:** Minimal.

**EFFECTIVE DATE:** Upon the date of the approval of the form by the Commissioners of Health and Mental Retardation and Developmental Disabilities and shall terminate two years thereafter.
Can the Right to Stop Eating and Drinking be Exercised via a Surrogate Acting Pursuant to an Advance Instruction?

Posted on January 23, 2017 by Norman Cantor

by Norman L. Cantor

The right of a grievously stricken, competent patient to hasten death by ceasing eating and drinking is increasingly recognized. In the typical scenario, a person afflicted with a serious degenerative disease reaches a point where the immediate or prospective ordeal has become personally intolerable. The stricken person decides to shorten the ordeal by stopping eating and drinking, precipitating death by dehydration within 14 days. The dying process is not too arduous so long as there is a modicum of palliative care available – emotional support, lip and mouth care, and provision of a sedative if patient agitation or disorientation ensues.

A further question is whether a person can dictate a similar fatal course for his or her post-competence self by advance instruction to an agent. The instruction would be that — once a pre-defined point of dementia has been reached — either no food or drink should be offered to the incompetent patient or no manual assistance should be provided where the patient is not self-feeding. This post-competence SED tactic appeals to persons who view the prospective demented status as intolerably demeaning and wish to hasten their demise upon reaching that state. The legal claim would be that if a competent patient has a right to SED, the right ought to subsist post-competence when exercised by clear advance instruction. According to this claim, just as an advance instruction to reject a respirator would be upheld as an exercise of prospective autonomy, so an instruction for cessation of nutrition should be respected.

A person who undertakes responsibility for a demented person normally has a fiduciary duty to promote the well-being, comfort, and dignity of the ward. A guardian who forgoes available care measures such as shelter, warmth, hygiene, and food is chargeable with unlawful neglect. Provision of food and assistance in eating are normally part of that fiduciary obligation. A legal exemption might apply, though, if the guardian — in
discontinuing hand feeding pursuant to an advance instruction — is simply respecting the right of the ward to exercise prospective autonomy. The question becomes: Is the acknowledged right to SED exercisable by means of an advance instruction?

As a person intent on avoiding being mired in deep dementia, I wish I could declare that the described post-competence SED tactic is legally sound. But I can’t. In the form it is currently recognized, the right to SED cannot readily be translated to the context of a moderately demented person. Here’s why.

A competent stricken patient who hastens death by initiating SED is not simply invoking the well-established liberty right to reject life-sustaining medical intervention in order to let a natural affliction take its course. Unusual suicidal overtones are present. For example, an ALS patient who stops accepting food and drink is undertaking a deviant course (SED) that will precipitate death. The proximate cause of death will be self-initiated dehydration rather than the underlying ALS disease process. Common judicial willingness to overlook the suicidal overtones, and to accept a right to SED, hinges on 2 factors: a) a patient’s contemporary judgment that the serious medical affliction entails such intolerable debilitation and/or suffering that death by dehydration is preferable; and b) the repulsive inhumanity of the prospective medical intervention. (In the context of a stricken person determined to resist feeding, the contemplated medical solution — forced feeding — involves unwanted bodily invasions and physical or chemical restraints widely deemed inhumane).

Neither of these factors underpinning the right to SED is present once a patient is no longer mentally competent. The stricken patient is no longer capable of deciding that the current deteriorated status is so intolerably undignified or distressing that death by dehydration is preferable. And the contemplated medical intervention — hand feeding to a willing patient — entails no revolting indignity. Without these elements, even with an advance instruction in hand, a surrogate decision maker who seeks to initiate SED for a moderately demented patient willingly accepting oral feeding is treading in euthanasia or assisted dying territory. The legal toleration for self-destruction implicit in acceptance of a “right” to SED might well not be extended to a now-demented patient.

All this does not mean that advance directives are inapplicable to post-competence matters of nutrition and hydration. For when hand feeding becomes a form of medical intervention, a person’s prerogative of using prospective autonomy (advance instructions) to shape post-competence medical treatment does come into play.

This prospective control of medical intervention is not dependent on living will statutes with their typical constraints like a “terminal illness” requirement. Long before widespread living will legislation, prominent courts recognized that a patient’s basic common law right to control medical measures extends to a post-competence stage so long as clear prior
instructions exist. State courts led the way in ruling that a person's common-law and/or constitutional liberty to control medical choices does not vanish upon incompetence. E.g., In re Browning, 568 So.2d 4 (Fla. 1990); In re Jobes, 529 A.2d 434, 451 (N.J. 1987). The U.S. Supreme Court concurred in dictum in Cruzan. This judicial recognition is reinforced in the many states that statutorily provide for advance appointment of health care agents with authority to make the same range of medical decisions as competent patients. Such statutes commonly require the designated agent to implement the patient's known wishes concerning post-competence medical care.

This "prospective autonomy" legal framework for post-competence cessation of nutrition is applicable where the relevant feeding techniques qualify as medical intervention. For example, where dementia produces swallowing or digestive disorders necessitating ANH (by nasogastric tube or PEG tube), medical intervention is clearly in issue and the now-incompetent patient's prior instructions should govern.

The harder question is whether hand feeding necessitated by common eating deficits accompanying progressive dementia qualifies as medical treatment. Reduced nutritional intake can flow from cognitive decline (such as non-recognition of food or eating utensils) or physical deterioration (such as loss of mechanical skills for self-feeding). From one perspective, hand feeding is then a therapeutic "medical" response to pathology associated with the degenerative affliction. However, if the demented patient is still willing to eat and is accepting hand feeding, and eating assistance can be performed by non-medical personnel, such feeding might be classified as basic personal care rather than medical treatment. (Whether basic personal care can be rejected by a binding advance instruction is an open issue).

Even if the presence of an eating disorder emanating from dementia qualifies manual feeding as medical intervention, implementation of an advance instruction rejecting hand feeding is fraught with hurdles — at least at stages of decline preceding advanced dementia. Keep in mind the common profile of a moderately demented person. Despite significant cognitive debilitation, that person is not perceptibly suffering and may ostensibly be deriving modest pleasures from life. (E.g., listening to music). That moderately demented person no longer recalls his or her once strong aversion to the perceived indignities of debilitation and dependency. I.e., that person no longer remembers their previously expressed determination to reject hand feeding in order to hasten their post-competence demise. In those circumstances, even a clear prior instruction to forgo all forms of nutrition and hydration faces complications or challenges in implementation.

The first complication relates to the nature of the dying process for the moderately demented person whose advance instruction rejects all nutrition, including hand feeding, at the stage of cognitive decline now at hand. A competent person who undertakes SED needs a resolute will to overcome normal hunger and thirst pangs as well as to resist
entreaties from people opposing the fasting plan. That resolve must remain firm for 6 to 10 days until the fasting patient slips into coma; ingesting even small amounts of nutrition or hydration may substantially prolong the dying process. A moderately demented person may lack the requisite motivation and determination, thus creating potential for a much more protracted and distressful dying process. Such a person might be expecting and seeking food and drink and might be distressed by their absence. Some caregivers might then capitulate to sporadic entreaties and provide nutritional intake extending the dying process.

On the other hand, perhaps palliative interventions (sedation) can ease the confusion or agitation of the moderately demented patient. And perhaps some demented patients will be unperturbed and indifferent to absence of nutrition. In such instances, a placid death by dehydration might be available for the demented patient. In short, the process of death by dehydration for an uncomprehending patient is uncharted territory. A modicum of dignity in the dying process might, or might not, be available in the context of surrogate-initiated cessation of hand feeding.

Another potential obstacle to post-competence SED is caregivers’ reluctance to cooperate with a surrogate-initiated cessation of hand feeding. Some physicians, nurses, or health care aides see provision of food and water by mouth as a symbolic gesture of caring for fellow humans that is demanded by the caregivers’ ethical or conscientious principles. Such moral compunctions may also underlie institutional policies (in Catholic and some other elder-care facilities) opposed to withholding of hand feeding. Professional and institutional reluctance to cooperate with non-feeding will be most intense where the moderately demented person is still engaged in positive interactions with their surroundings. While the conscientious objections of some caregivers should not override a clearly expressed advance rejection of medical intervention, finding replacement caregivers may pose a significant practical obstacle to implementation of the advance instruction declining hand feeding.

A final challenge lies in interpreting the conduct of a demented patient who is now seeking or accepting hand feeding despite a prior instruction rejecting post-competence hand feeding. A person who dictates an advance instruction is entitled to change their mind and revoke. Does a demented patient’s acceptance of hand feeding or utterance of a verbal request for food and drink constitute an effective revocation of a prior instruction?

A counter perspective is that the demented, uncomprehending patient is acting by reflex rather than by volition or is being manipulated by surrounding people exploiting the suggestibility of the now-incompetent patient. The legal reality is that no established judicial standard exists for assessing cognitive capacity needed to revoke an advance instruction invoking a right to prospectively reject medical care. Note that statutes speaking to living wills typically make advance directives revocable even by
post-competence utterances. These statutes don't apply to prospective exercise of the basic common-law right to reject medical intervention. But they still reflect a customary willingness to defer to contemporaneous life-extending expressions - even from mentally incapacitated persons. And at least one court has ruled that a totally uncomprehending acceptance of spoon feeding is legally sufficient consent to hand feeding. See Bentley v. Maplewood Seniors Care, 2014 BCSC 165 (Feb. 2014), affirmed 2015 BCCA 91 (British Columbia Ct. App. 2015). (That case did not deal with a clear-cut prior instruction rejecting hand feeding).

What, then, are the tentative conclusions regarding the legal status of advance instructions rejecting post-competence hand feeding? One is that the recognized right of a competent, stricken patient to SED is not readily translatable to the context of a now-incompetent patient. Another is that a legally sound theoretical framework exists for enforcing advance instructions to reject nutrition and hydration, including hand feeding, so long as the hand feeding can be classified as medical intervention necessitated by pathologies associated with progressive dementia. Despite that sound legal framework, though, a variety of complications or hurdles exist in implementing an advance non-feeding instruction regarding a moderately demented patient (as opposed to a patient who has reached advanced dementia).

These complications or hurdles face any person whose aversion to the indignities of cognitive debilitation fuels a desire to hasten death once a significantly demented status has been reached. That desire might prompt advance instructions to forgo even the most simplistic medical interventions such as antibiotics for any infection. Such instructions encounter an instinctive human reluctance to hasten the death of a person who, while cognitively debilitated, is not suffering, derives some satisfaction from continued existence, and no longer recalls the dignity and life-image concerns that motivated a prior instruction to forgo even simplistic medical interventions. That topic goes beyond provision of nutrition and hydration and deserves to be addressed further. Stay tuned.

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Changing the Paradigm of Advance Directives to Avoid Prolonged Dementia

Posted on April 20, 2017 by Norman Cantor

by Norman L. Cantor

In the early days of living wills — the 1970’s and 1980’s — a major objective was to avoid being maintained on burdensome medical machinery in a highly debilitated status at the end stage of a fatal affliction. The contemporaneous legislation endorsing advance directives was typically geared to “terminal illness” (meaning likely death within 6 months). The distasteful specter was a moribund patient tethered to burdensome interventions like a respirator or a dialysis machine despite an unavoidable, looming demise. A common short-form living will rejected life support that “only prolongs the dying process” for a patient in “a terminal condition.”[i]

Another specter was being medically sustained in an utterly dismal quality of life — such as permanent unconsciousness without awareness or interaction with one’s environment. The contemporaneous legislation explicitly authorized advance directives seeking to avoid medical maintenance in a permanently vegetative state. And several landmark cases authorizing surrogate end-of-life determinations involved permanently unconscious patients. See Quinlan (N.J. 1976); Brophy, (Mass. 1986); Browning (Fla. 1990); Schiavo (Fla. 2005).

With the increasing prevalence of Alzheimer’s disease and similar degenerative dementias, the focus of advance directives has changed for some people. The primary specter is neither an unavoidable looming demise nor the insensate limbo of permanent unconsciousness. Rather, the emerging concern is protracted maintenance during progressively increasing cognitive dysfunction and helplessness. For some, being mired in a demented state is an intolerably degrading prospect well before the advanced stage when the person no longer recognizes loved ones and is totally comprehending.

For people like me who see even moderate dementia as an intolerably demeaning status staining their life image, their advance directive may seek to facilitate death by declining even simplistic medical interventions like antibiotics. Our hope is that death will soon ensue when an infection is left untreated or when artificial nutrition and hydration is withheld in the face of an eating disorder.
This new paradigm for an advance directive – avoidance of prolonged dementia – seeks to accomplish the demise of persons who, without such a directive, would surely be medically sustained. For a dignity-focused advance directive envisions hastening the demise of a demented person who may not perceptibly be suffering, who may be getting some rudimentary satisfaction from a debilitated life, and who may no longer recall the directive’s underlying preoccupation with a personal vision of intolerable indignity. Can and should such an advance directive be implemented?

Some medico-legal commentators express moral compunctions about surrogates allowing an uncomprehending, ostensibly content individual to die.[iii] These commentators focus on the experiential interests of the now-incompetent person. For them, the demented person’s previous dignity-based concerns have been forgotten and are now irrelevant. For them, a surrogate’s moral obligation is to prevent the "harm" of avoidable death for a non-suffering, demented patient – regardless of contrary advance instructions.

For me, these moral claims are both unconvincing and counter to the prevailing legal frameworks. Overriding clear, considered advance instructions declining medical intervention at a point of self-defined intolerable indignity is itself a serious harm – even if the now-incompetent patient can no longer comprehend the violation of previous wishes.

American law and custom respect prospective autonomy (or precedent autonomy) in various contexts. These contexts include the disposition of property via contract, irrevocable trust, or last will and testament, as well as organ and tissue donation and disposal of mortal remains. And they include a prerogative of a competent person to shape the medical fate of their future demented persona according to personal values and visions of intolerable indignity. (That is the central function of an advance directive).

I have argued elsewhere that prospective control of a later, helpless persona is not immoral.[iii] While a later, demented self may have a very different character, personality, and memory set than a prior competent self, the 2 personas constitute a single person whose life narrative is unfolding in successive stages. The demented persona has the same body, the same spouse, the same relatives, the same property, the same religion, and (I argue) the same principles as its competent predecessor. The self-determination prerogative (dominion over the medical fate of a future persona) has, I contend, been earned by the competent person who nurtured and developed the body, character, relationships, and lifetime images associated with the later, incompetent persona.

American law upholds efforts of competent persons to control the medical fate of their subsequent incompetent personas. Starting with Quinlan in 1976,[iv] landmark opinions have established a fundamental right of competent persons to reject (or accept) life-sustaining medical interventions. This right is grounded in self-determination and bodily integrity and is anchored by various courts in the common law, state constitutional
provisions, or the liberty clause of the 14th Amendment of the federal constitution. Importantly, the same courts declare that a competent person's right to control medical intervention is not lost by onset of incompetency. If the now-incompetent patient has left clear instructions regarding post-competence medical handling, those instructions effectuate the patient's right to control medical intervention. The widely prevalent legal standard for surrogate medical decisionmaking -- substituted judgment -- dictates adherence to prior instructions and thus secures for an incompetent patient "the same panoply of rights and choices" as accorded to competent persons.[v] Moreover, prevailing medical ethics also dictate upholding a now-incompetent patient's prior treatment choices even in the face of a physician's differing value judgment about remaining quality of life.[vi]

That an advance instruction withholding life-sustaining medical intervention from a helpless, non-suffering demented person is both lawful and moral does not mean that it will be readily implemented. The medical treatment of an incompetent patient is in the hands of a designated agent (or other surrogate) along with attendant care providers. For them, it cannot be easy to allow the preventable death of an individual who still derives some rudimentary satisfaction from life, even if that was the patient's express wish.

It will take a resolute, committed agent or surrogate to secure implementation of the contemplated dignity-based instructions. The declarant in an advance directive cannot rely on legal sanctions to enforce the advance instructions. Courts are not likely to punish surrogate decision makers or care providers for failure to facilitate the death of a non-suffering patient who no longer recalls his or her dignity-based instructions. The damage flowing from maintenance of life contra to prior instructions is not readily calculable in monetary terms.[vii]

Even without an efficient enforcement mechanism, a declarant can include advance directive provisions that enhance the prospects for implementation of dignity-grounded instructions. The following is my own, revised advance directive geared to avoiding prolongation of life in a demented state that I deem intolerably undignified. It invokes my common-law and constitutional prerogatives to shape my post-competence medical fate.[viii] It includes provisions that should reinforce the resolve of my decision-making agent and should assist that agent in overcoming any resistance from care providers or others.

My Revised Advance Directive

I have witnessed the ravages that Alzheimer's disease and similar progressive dementias produce. I wish to be allowed to die upon reaching a degree of permanent mental dysfunction that I deem to be intolerably demeaning. For me, this means mental deterioration to a point when I can no longer read and understand written material such as a newspaper or financial records such as a checkbook.
This wish to hasten my post-competence demise is not based on prospective suffering or distress, but rather on my personal vision of intolerable indignity and degradation associated with cognitive dysfunction. For me, it is critical to shape the post-mortem recollections of my loved ones and to preserve the lifetime image as a vital, critically thinking individual that I have strived to cultivate. In addition, it is important to me to avoid being an emotional, physical, or financial burden on my family and friends, even if they would willingly assume such burdens.

I fully understand that my determination to avoid prolonged, progressive debilitation could prompt my demise even though I might appear content in my debilitated condition. I am exercising my prerogatives of self-determination and bodily integrity to shape my lifetime narrative, including my dying process, in accord with my strong aversions to mental dysfunction and to dependence on others.

My determination not to prolong my life at the described point of debilitation includes rejection of any and all life-sustaining means. This includes simplistic medical interventions such as antibiotics, blood transfusions, and anti-arrhythmics, as well as more complex interventions like CPR, mechanical ventilation, dialysis, and artificial nutrition and hydration. Indeed, if my dementia or any other affliction has produced inability or unwillingness to feed myself — for example, because of swallowing difficulties, or other eating disorders, or just indifference to eating — I instruct that my caregivers refrain from hand feeding unless I appear receptive to eating and drinking (show signs of enjoyment or positive anticipation). If I am indifferent or resistant to hand feeding, I do not want to be cajoled, harassed, or in any way impelled to eat or drink.

The only limitation on my advance rejection of life-sustaining medical intervention is adherence to humane treatment. That is, I have no desire to subject my future incompetent persona to a torturous or agonizing dying process. I presume that palliative steps — including medication for pain, anxiety, or agitation — will be taken to ease my dying process.

The question may arise as to whether I have had a change of mind and revoked my advance directive. My wish is that no revocation be found unless I do so while still capable of a considered choice, including appreciation of all the major elements involved. I urge my decision-making agents to avoid the temptation of manipulating my future, incompetent persona to contradict or alter my advance instructions. And I direct that my original instructions be honored absent an aware, considered change of mind (as opposed to uncomprehending expressions by my demented persona).


[vi] AMA Principles of Medical Ethics, Current Opinions of the Council on Ethical and Judicial Affairs, Sections 5.2(e) & 5.3 (2016).

[vii] There are occasional damage suits or administrative proceedings brought against medical personnel and institutions for violating advance directives rejecting life support. See T.M. Pope, Legal Briefing: New Penalties for Disregarding Advance Directives and DNR Orders, 28 J. Clin. Ethics 74 (Spring 2017). Such proceedings offer encouraging signs for enforcing implementation of advance directives, but they do not yet constitute a strong impetus to honor advance directives. This is so in part because some courts may
insist that monetary damages, such as for pain and suffering or for costs of unwanted medical services, be set off against the presumed intrinsic value of extended human life. See generally H. Fernandez Lynch, M. Mathes, & N.N. Sawicki, Compliance with Advance Directives: Wrongful Living and Tort Law Incentives, 29 J. Legal Med. 133-78 (2008).

[viii] Because my directive is grounded in common-law and constitutional rights, it is not constricted by preconditions, such as a "terminal" condition, contained in some living will legislation. Such living will statutes cannot override constitutional prerogatives and they generally do not purport to. Most living will statutes contain a "savings" provision preserving the existing common-law and constitutional prerogatives that a patient has, including the prerogative to leave advance medical instructions. See K.L. Cerminara & J.R. Kadis, Give Me Liberty to Choose (A Better) Death: Respecting Autonomy More Fully in Advance Directive Statutes, 10 J. Health L. & Policy 67, 70-73 (2016).

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About Norman Cantor

Norman Cantor is Distinguished Professor of Law Emeritus at Rutgers University School of Law, Newark. He taught in the fields of Constitutional Law, Contracts, and Bioethics (Death, Dying, and the Law). He has been widely published in legal and medical journals on the topic of the legal handling of dying medical patients. His books are: After We Die: The Life and Times of the Human Cadaver (2010); Making Medical Decisions for the Profoundly Mentally Disabled (2005); Advance Directives and the Pursuit of Death with Dignity (1993); and Legal Frontiers of Death and Dying (1986). Professor Cantor is a cum laude graduate of Princeton University and a magna cum laude graduate of Columbia Law School where he served as Notes and Comments Editor of the Columbia Law Review. He has served as a visiting professor at Columbia University, Seton Hall University, Hebrew University of Jerusalem, and Tel Aviv University. He currently divides his time between Hoboken, N.J., and Tel Aviv.

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3 THOUGHTS ON "CHANGING THE PARADIGM OF ADVANCE DIRECTIVES TO AVOID PROLONGED DEMENTIA"
Advance Directives, Dementia & Decisions About Hand Feeding

“What did I do wrong?” Ann asked me as we stood at the foot of her mother’s bed, and watched an aide patiently coax her to open her mouth with soothing terms of endearment. When the aide gently brought the spoon to the side of Hannah’s mouth, it popped open, like a baby bird’s mouth. She spooned the pureed ‘food’ into her mouth and Hannah swallowed with seeming relish, without evidence of physical difficulty and no coughing or choking. It takes at least an hour to feed Hannah each meal. The aide, one of a group of round-the-clock aides who are overseen by a home hospice program, crooned endearments to the woman she has cared for during her lengthy illness.

Ann and Hannah consulted an attorney before completing her advance directive. After careful discussions with her mother, Ann knew she would never want to receive tube feedings or other life-prolonging medical interventions if she had a terminal illness or was in great pain and couldn’t make her own treatment decisions. But nobody ever advised Ann or Hannah to consider the problem of advanced dementia and hand feeding.

Hannah, now 98, was diagnosed with Alzheimer’s disease 15 years ago and was deemed to be in the terminal stage of the disease over a year ago. She has been bed-bound and in diapers for the past 7 years and now lies in bed - mute, motionless, and unresponsive. She seems unable to recognize her daughter or any of her long-time caregivers. She is very thin; Ann sorrowfully described her as “a bag of bones.” She said her mother would be horrified if she could see herself lying helplessly in a hospital bed in diapers, in the living room of her New York City apartment. If she could speak, Ann said, she would say “Just shoot me now.”
Ann first contacted me in the hope that I could help her mother to die (legally, of course). Initially I thought that Ann, as her mother’s appointed health care agent, could simply decide to forgo all life-sustaining measures (in this case nutrition and hydration) because that was the choice her mother would make if she were able to speak and could appreciate her current stage of advanced dementia. But then I observed Hannah readily opening her mouth and swallowing whatever was put into it and the problem came into sharper focus.

Absent a very specifically written advance directive stipulating that hand/assisted feeding be stopped once a particular stage of advance dementia occurs, Hannah will continue to be fed indefinitely, regardless of any pleas to the contrary by her daughter. In time, Hannah will “forget” how to swallow and will begin to cough and choke when she is fed. Or she will no longer open her mouth. Only then will the hospice clinicians acknowledge that the burdens of continued feeding now outweigh the ‘benefits’ of continued life – even though Ann and her mother would have chosen a much earlier time for that determination. Ann pays out-of-pocket for the 24 hour care her mother receives and, while she is grateful that she still can afford this, she worries about the time when she will no longer have the resources to do so.

The inclusion in an advance directive of specific instructions to forgo hand feeding if an advanced stage of Alzheimer’s or other dementia occurs is a relatively new development in the realm of advance medical planning. But, as more patients are diagnosed with an early stage of Alzheimer’s disease, we are hearing from some who want to know if there is any way to avoid the final stages of severe dementia.

Today there are 390,000 New Yorkers diagnosed with Alzheimer’s disease. By the year 2025, it is expected that there will be 460,000. Some of those individuals will NOT want to be hand-fed
in the final stages of the disease but, without a directive explicitly stating the wish not to be hand
fed, nobody will know, and they will probably be fed indefinitely. The NYS Health Care Proxy
law stipulates that an appointed agent must know the patient’s wishes about artificially/medically
provided nutrition and hydration before being authorized to decide about its use, but the law is
silent on the issue of assisted oral feeding. Although there is not yet judicial or legislative
recognition of the validity of such instructions, we hope there soon will be. And in the meantime,
those who feel strongly about this issue should document their wishes in a written directive so
that others will know their wishes, and their health care agent can then advocate for those wishes
in the event that advanced dementia occurs.

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Bibliography

Articles


Booklets

Using Advance Directives to Avoid Prolonged Dementia: The Clinical Reality

Judith K Schwarz, PhD, RN
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Aging Law Series, Albany Law School
June 6, 2017
Plan to discuss

- Role as Clinical Director of EOLCNY
- Usual reasons New Yorkers call for consultations
- **Now** hearing from New Yorkers diagnosed with early stage of Alzheimer’s disease (AD)
- What I advise & what happens with & without that information & support – 3 cases
End of Life Choices New York

• In NY for 15 yrs – previously known as Compassion & Choices of NY
• A not-for-profit organization providing information, advocacy & support for New Yorkers trying to make best end of life choices for themselves
• Mission: to improve care & expand choice at end of life
• Advocate for improved health care law with colleagues in hospice & palliative care
New Yorkers call for lots of reasons

- Simple questions like advance directives, where to get them, different forms & how to fill them out
- Other questions more challenging — e.g. how to control or hasten timing of death LEGALLY in NY
- If terminally ill — help enroll in home hospice care — if disease incurable/progressive get them palliative care
- Caller must be decisionally capable & have family or other social support
- Often patients are elderly with lots of medical problems & often tell me they are DONE!
Often, only legal option to hasten death

- **Voluntarily Stopping Eating & Drinking (VSED)**
- No one’s first choice
- Requires person who is: decisionally capable & VERY determined to hasten death due to unbearable suffering; has care-giving & family or social support + access to hospice or palliative medical over-sight
- Results in *fairly* peaceful, gentle death within days to 3 wks (depending upon underlying disease & physical condition)
- Cause of death is dehydration not starvation
Now callers with NEW diagnosis

- Previously heard from those with incurable progressive diseases not yet terminally ill
- And some had dementia as secondary symptom of other diseases (e.g., end stage Parkinson’s disease)
- Had not previously heard from those newly diagnosed with Alzheimer’s disease (AD) – numbers increasing
- In 2016 New Yorkers with AD age 65-75 = 51,000
  - age 75-84 = 160,000; > 85 yrs = 180,000
For those with early stage of dementia

- While retain decision making capacity
- Can decide to fast [onto death] while capable of making informed decisions AND able to remember decision made
- VERY challenging option - need lots of support
  timing is everything – it becomes too late once decision making window closes
- Alternative is to complete very comprehensive written directive while competent - stipulating that assisted or
  hand feeding be withheld once decision making capacity & ability to self-feed are lost
WHO would make such a choice???

- Self-selected group who care passionately about HOW they die & want desperately to avoid disease’s final stages
- Often have family history of dementia & have observed the lingering/undignified death of loved ones
- For some, the ‘terminal’ stage of dementia, i.e. bed-bound, unable to speak or recognize loved ones, incontinent of urine & stool = a fate actually worse than death
- Terminal stage of AD can last for more than a year – PROVIDED the patient is hand fed by another
Requires careful, thoughtful discussion

- Initial consultation is with patient + most significant family member &/or appointed health care agent
- Subsequent conversations include other family members & stakeholders
- Best to get legal & medical buy-in for written directive while patient retains decision making capacity
- Include statement: “Even though I may appear to cooperate in feeding – the reflexive opening of my mouth when spoon touches my mouth does NOT constitute a change in my prior refusal to be hand fed.” once an advance stage of dementia occurs
Three cases to compare & consider

• Hannah 98 yrs diagnosed with AD 15 years ago
• In ‘terminal’ stage for more than a year; bed-bound, in diapers for past 7 years; no longer speaks or seems to recognize only child or long-time care-givers
• Is carefully spoon-fed 3 meals each day by 24/7 aides
• Each meal takes more than an hour but, with verbal encouragement, Hannah opens her mouth & appears to enjoy the glop she swallows without signs of coughing, choking, or other distress
Hannah, continued

- Hannah, her husband & daughter Ann all worked in their successful family business
- After husband died, Hannah & Ann went to family attorney to complete an advance directive
- Ann & Hannah had careful discussion re her EOL wishes & concerns
- Ann knew Hannah would never want life-prolonging measures like feeding tube or resuscitation
- But nobody advised them to consider whether she would want to be hand fed if suffering advanced dementia
Hannah continued

• Even though Ann knows her mom would be horrified if she could see herself now & would say “Just shoot me!”

• While Hannah continues to readily open her mouth she must be fed BECAUSE there is no previously completed directive indicating a decision/choice NOT to be fed

• Hospice confirms…until she starts coughing or choking or resisting being fed – in the absence of prior directives to the contrary, she will continue to be fed indefinitely

• Ann hopes she doesn’t run out of money before that time
Peter, wife Sandra & 4 adult kids

- Contacted by Sandra for assistance helping Peter complete advance directive
- Peter diagnosed w AD a year ago; he rejects diagnosis; says he has always been ‘forgetful’
- Sandra & kids say this forgetfulness is different
- Peter has always believed in EOL choice & wanted to complete a directive saying “If I EVER GET Alzheimer’s, I want to stay at home (no nursing home) & do not want to be fed if I can’t feed myself & have lost decision-making capacity”
Peter continued

• Had several meetings with Peter, Sandra, both sons & daughters after he completed written directive
• Peter told all family members: if he suffered from moderate to severe dementia – he would want to die as quickly as possible at home, without suffering & no one should give him any food or fluid even if he asked for it (even if he forgot his previous decision to fast)
• He seemed quite disinterested in how difficult this might be for his family to manage.
• We meet at least once a year…all of us….to evaluate any changes in his wishes….or in his condition
Final case - Brian & Judith

• Judith contacted me for a consultation for her & husband Brian to discuss EOL options for him

• Brian is a Pulitzer prize-winning author who was diagnosed with AD several years ago & is horrified at prospect of losing his mind

• During initial discussion of possible options that would permit him to control timing of death he asked “What if I just take a gun & kill myself ?”

• Spent a long time discussing VSED &/or completing a written directive to SED once dementia ‘moderately severe’ & capacity is gone along with ability to self-feed
Brian continued

- They completed the written directive stipulating that hand feeding be withheld if dementia progressed to moderate stage & he was unable to self feed
- They took copies of document to family attorney & primary care physician – an old friend & supportive
- He moved to a ‘high end’ assisted living facility
- Judith called & told me Brain recently said he would soon have to begin to fast as he could no longer complete thoughts
Brian continued

- The plan was for Brian to come home to fast with hospice support – arranged by pri care physician
- Judith called late one night in tears...her sister-in-law had called her a murderer for suggesting this plan
- Suggested sister speak NOW – to Brian about HIS wishes & eol concerns + view the written directive
- She called 2 wks later to say her daughter, a MD, wondered whether Brian might still experience some “joy” even if severely demented
- Suggested she also speak to her dad & view the directive
In conclusion

- These cases are, in reality, very complicated
- But some folks diagnosed with an early stage of AD care enough about avoiding the final stages of dementia that they take the time & energy to complete a comprehensive directive saying how their ‘incompetent’ self should be treated....
- Those instructions should be honored – as any other carefully considered advance directives ought to be honored...
Thank you...

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Alzheimer’s Disease and Advance Directives: Bringing the Conceptual Confusion Into Clinical Focus

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Objectives

• Highlight the urgency to address some basic obligations in the care of Alzheimer’s patients

• Emphasize that Alzheimer’s patients are a continuous human being over time with continuous interests throughout clinical care

• Show that advance directives are important tools that depend upon a viable plan of comfort care
Alzheimer’s: Key Facts

- Neurodegenerative, terminal disease—currently untreatable
- Accounts for 60-80% of dementia cases
- Eventually results in loss of capacity
- Median survival after diagnosis 3-9 years
- Increasing age is greatest risk factor
- Accounts for over 500,000 deaths per year
A Growing Crisis

• Eldest Baby Boomers reached Medicare eligibility in 2011
• Affects 1 in 9 older Americans, nearly 1 in 3 over age 85—nearly 6 million individuals
• Fewer than 8% of Americans have long term care insurance
• Costs to healthcare system around $214 Billion
• Costs to unpaid caregivers around $220 billion—majority of whom are women
Dramatic Impact On Patients’ Quality of Life

• Fading self-awareness
• High risk of depression
• Loss of capacity
• Eventually,
  – The patient lives in a world of discrete moments and
  – Requires full time caregiver support
Lost Window Of Opportunity

- Many newly diagnosed Alzheimer’s patients have capacity
- These patients have a right to receive full disclosure of their diagnosis and its natural progression
- Which is to say, physicians, many in the primary care setting, have an obligation to honor this right
- Over half the time, this obligation is not met
Patients Are Left Vulnerable

• Unable to plan for the future
• No opportunity to complete advance directives and define the care goals when the patient loses capacity and approaches the end of life
• Greater risk of burdensome, needless, and costly medical interventions
• Default option is to provide aggressive medical treatment—possibly causing harm
Perceived Physician Barriers To Initiating Conversations

- Lack of time
- Lack of comfort and knowledge
- Fear of overwhelming the patient with bad news
- Not there yet—time to wait on things to progress
Time To State The Obvious

• Physicians have a clear obligation to provide full disclosure of diagnosis and prognosis to all patients with capacity

• We need a paradigm shift similar to what happened in the care of cancer patients from 1960 to 1979

• Time to demystify Alzheimer’s disease and treat it like all other diseases
Larger Lurking Issue

- Progressive neurological disease—continual changes in states of awareness and preferences
- Common belief: Preferences are in flux—no stable self
- Implication: No clear end of life planning options for patients with progressive dementia
- Debate has complicated advance care planning for both physicians and patients
The Now Vs. Then Self In Dementia Patients

• The former self that was autonomous and able to express critical interests—the then self

• The current self—the now self—has no recollection of the former then self—and may have preferences, based on experiential interests, contrary to what was formerly cherished as a foundational value
Dilemma: Which Preferences Have Moral Say?

- Should preferences that reflect autonomous, critical interests be adhered to regardless of future changes?
- Or, do changes in preferences reflect a series of disconnected selves, each with its own, fleeting moral authority?
- On either assumption, advance directives become practically challenging if not impossible to implement.
The Alzheimer’s patient with capacity is a single human being in whom there is a unity of critical and experiential interests when capacity and critical interests wane, experiential interests continue, often in tact for some time—become crucial components of comfort care. The evolving patient persists with changing experiential interests and needs over time—the same patient!
Qualifying All Preferences

• Preferences of a patient with capacity expressing critical interests in the present, OR preferences expressed in advance directives must be actionable

• Usually that means are within certain ethical, legal, and practical parameters
Please Don’t Feed Me!

- Most caregivers (medical and family) would uncomfortable to not provide food and water to demented patient
- Caregiver sentiment is ethically supportable—not an actionable plan—Ulysses Contracts do not work here
- But also: Such a patient request fails to recognize the natural, human basis for human comfort, i.e. the experiential interests that persist even with dementia
Case Example: John

John is a 75 year old man in good health physically but shows clear signs of memory loss. After consultation with his physician, while his wife is present, his physician informs him of the likely diagnosis of Alzheimer’s disease and describes the likely prognosis in the coming months and years. Presently he has capacity to make his own decisions about current and future medical treatments.
Case Example: John (Con’t)

During the interaction with his physician, John expresses a clear desire to have maximum comfort care and to avoid pain and suffering beginning at the time of his office visit. Moreover, he states that he does not wish to live in a state of advanced dementia and wants his caregivers, including his wife, to do nothing to prolong his life. How would that preference play out?
Current Plan For John

• Right to refuse all life prolonging treatments—could be made DNR and DNH

• He can define his goals of care, including comfort care only—no artificial life supports

• Physician Assisted Suicide is not an option in 45 states—VSED is an option

• How might the plan for comfort care play out in John’s future?
John—3 Years Later

John remains in good overall physical health despite being fully demented and lacking capacity. He now lives in a nursing home facility where he is active and very social with other patients. He has a great appetite and heartily eats all of his meals. He is now in a condition that he ideally preferred to avoid—but no one was going to deny him food. But his quality of life overall seems good even though he no longer recognizes his wife, family, and friends.
Commentary

• John’s critical interests may appear to be in tension with his present experiential interests – but are they?

• John’s is not suffering and seems to be enjoying his life—food is a source of comfort—comfort care is in place

• Clearly he should not receive any burdensome, life prolonging interventions

• But what about antibiotics which could easily return him to his baseline?
John—Two More Years Later

John’s overall health has declined sharply. He is less active and no longer feeds himself at mealtime? He simply sits and stares at his food. He does not socialize and has become very withdrawn. Yet when John’s care providers hand feed him, he chews and swallows and seems to enjoy the experience.
Commentary

- Entering a gray area in terms of hand feeding
- Clearly G-Tube is not indicated
- If eating provides him pleasure, it could be justified, but with great caution
- Interests are starting to become more relevant to his situation and should be used to guide decision making (Menzel PT, Chandler-Cramer MC. Hastings Cent Rep. 2014; 44(3):23-37.)
John—2 Months Further Out

- As is typical of the disease progression, John’s interest in eating continues to wane. Now, when his care providers feed him he accepts the food, chews, and swallows, but he seems indifferent about food. He shows no signs of hunger when he does not eat and when he does he shows no signs of gratification or enjoyment.
Commentary

• Strong clinical indication that hand feeding is no longer appropriate—could be stopped

• Clearly when he shows no interest in eating and is refusing to chew and swallow—hand feeding should be stopped

• He should only be given water if he accepts it

• John is actively dying—needs hospice care
Conclusions (I)

• Urgency to have systematic standard of care for Alzheimer’s patients across the healthcare system—from diagnosis to options for end of life care

• Physicians have an obligation to provide full disclosure and prognosis

• Alzheimer’s patients, like all patients, are evolving, unified human beings across time—from full capacity to advanced dementia
Conclusions (II)

• There is tension at times between a patient’s critical interests and experiential interests but they can be balanced.

• Patients with capacity can meaningfully state their advance wishes about medical care—within some limits.

• Many of the alleged problems about advance directives are based on a defiance of those limits.
Conclusions (III)

- Advance directives are important planning tools for Alzheimer’s patients and can help patients avoid burdensome treatment.
- Physicians need to understand the trajectory of comfort care, and educate patients and their caregivers.
- Critical interests should be respected within ethical and legal parameters based on continual clinical assessment.