Can We Let Patients Starve Themselves to Death—
Even If They Have Dementia?
And Can We Get Paid For It?

Ethics and Reimbursement at the End of Life

David N. Hoffman, JD
Lecturer in Bioethics, Columbia University
Chief Compliance Officer. Carthage Area Hospital

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Health Care Compliance Association
Compliance Institute

Questions:

- As the incidence of dementia increases there is growing awareness among patients of their ability to make decisions about care including explicit refusal of assisted oral feeding, even while receiving symptom management through hospice or palliative support. Should we support them?

- Why are clinicians and institutions often reluctant to support a patient’s decision to refuse oral feeding, particularly in the presence of dementia? It is often due to misunderstandings about the CMS definitions of Abuse, Neglect and Immediate Jeopardy?

- Various regulatory and reimbursement challenges—including CMS charges of failure to provide adequate nutrition and hydration to support and maintain life—which providers and institutions must confront when managing care for patients who do not want to eat, are real. What should we do about that?
Plan for today – Discuss:

• Concerns faced by terminally & incurable ill patients and families
• Because all suffering cannot always be relieved some patients want to know how to legally hasten death →
• Voluntarily Stopping Eating & Drinking (VSED)

• Legal, clinical & compliance considerations

With special thanks to my friend and colleague

Judith Schwarz, PhD, RN
Clinical Director, End of Life Choices NY

For her advocacy and contributions to this presentation
What is VSED??

- VSED is a manner of deliberately hastening death by deciding to stop consuming food & fluids while still physically able to eat & drink
- It is an intentional & voluntary choice by a decisionally capable person who suffers intolerably from an incurable, progressive or terminal illness with the goal of hastening his/her death
- Distinct from frequently occurring diminished appetite often experienced by dying persons
- Rarely 1st choice but often ONLY legal option

What is a successful VSED outcome?

How is success defined?

- VSED is legally available in all states IF person decisionally capable & makes voluntary (i.e. uncoerced) informed & contemporaneous choice
- A ‘successful’ outcome = peaceful death with minimum of discomfort occurring within a predictable period of days or weeks (my definition)
- Cause of death is dehydration not malnutrition
Four ingredients necessary for successful VSED death?

1. Decisionally capable, suffering pt who is VERY determined to hasten death by fasting
   - must understand the process, know what to expect & have concluded burdens of living consistently out-weigh benefits of continued life (This option is not for everyone!)
2. Must have both social & care-giving support
3. Must have access to hospice or palliative medical oversight
4. Must be able to be patient with the process

Clinical challenges to peaceful VSED death

- For those with terminal illness, forgoing food usually not difficult as appetite often diminished
- Forgoing fluids can be challenging – but with good oral care, rinsing & spitting, fine spray etc help relieve feeling of dry mouth
- Also – use of small doses of opioids & anti-anxiety meds → sleepy state
- Usual length of fast 7–14 days [aver. is 10] if fluids significantly limited & pt terminally ill
- Pt often slip into coma during final days
More challenges when patient NOT terminally ill

- Can be difficult to obtain palliative over-sight
  - sometimes long-time MD will order meds & provide palliative management or refer hospice
- Sometimes pt must fast for several days before considered eligible for home hospice support
- In absence of terminal illness – fasting can be more ‘challenging’ & last longer - up to 3 wks?
- Must be clear to all that patient’s suffering is intolerable & their decision to ‘escape’ is voluntary, well considered & very consistent

Ethical issues re VSED support

- Some question whether providing VSED support is morally equivalent to assisted suicide
- Those who believe it is always morally wrong for a person to hasten or cause own death may hold that providing information or support for VSED is also immoral
- Health care professionals are not obliged to provide care they find morally objectionable
- Claims of conscience permit withdrawing from case but NOT abandoning patient
ANA position statement re VSED

- 2017 ANA published “Nutrition & Hydration at the End of Life”
- Statement supportive of patients’ rights to make an informed choice to stop eating and drinking in order to hasten death
- AMA has not yet addressed this practice.

Diagnosis of those who contact EOLCNY

- Usually was advanced cancer – new diagnosis or return of previously controlled disease OR end stage ALS (Lou Gerick’s disease)
- Around 2016 began to hear from new group of patients & family members [often wives]
- Someone was diagnosed with an early stage of dementia...often Alzheimer’s disease
- Those w diagnosis were DESPERATE to avoid the final/terminal stage of disease that can last from months to YEARS
Dementia Data...

- 6 million Americans now have Alzheimer’s - number is expected to ↑ 14 million by 2050
- Advanced dementia (including Alzheimer’s) is 6th leading cause of death in US & the 5th leading cause for those > 65 yrs & 3rd for those > 85 yrs
- Although people can live well for several yrs w dementia – many want to avoid the final terminal stages
- There are SEVEN stages of declining abilities

Functional Assessment Staging Test

- Stages 1-3 mild cognitive decline: decreasing organizational capacity & memory challenges
- Stages 4-5 = Moderate Decline: can’t manage finances or complex tasks > can’t choose appropriate clothes for season or occasion
- Stage 6 = moderate/severe: unable to dress or bathe or mechanics of toileting w/o assistance & begins to be incontinent of urine & stool
- Stage 7 = advanced/terminal: ↑ loss of speech unable to recognize loved ones, can’t ambulate or sit up w/o assistance, CANNOT FEED SELF or smile
- This ‘terminal’ stage can last for months to years IF patient is hand fed
**Additional Alzheimer’s factoids**

- 10% of people 65 or ↑ have Alzheimer’s disease (AZD) or another dementia disease
- Older African Americans are twice as likely to have AZD as older whites
- Older Hispanics are 1.5 times as likely to have AZD as older whites
- 2/3 of Americans living w AZD are women
- As # of elderly Amer ↑ so does # of those w AZD
- ↑ early diagnosis b/c of development of biomarkers for disease → make EOL plans sooner

**Background to development of The Dementia Directive**

- Two West coast landmark cases focused attention on issue of assisted oral feeding
- Legal & philosophical scholars began thinking & writing about advance directives to limit oral intake
- First steps taken by sister organization EOLWA
- NY has had a difficult case & growing number of callers to EOLCNY have concerns about dementia
1st West Coast Landmark Case
• Margot Bentley of Vancouver BC, Canada
• 1991 - retired RN completed/revised living will & sent to daughters
• Wrote refused “..nourishment & liquids if suffering from extreme mental disability“
• Then suffered from Alzheimer’s > 17 years
• Spoon fed in nursing home for years despite family’s efforts & multiple unsuccessful court cases
• One judge ruled she had ‘changed her mind’
• Finally died 2015 @ age 83

The next slide is disturbing, but necessary,
2nd landmark case from Oregon

- Nora Harris, a research librarian
- 2009 ‘early onset’ Alzheimer’s at age 56
- Completed advance directive “to prevent her life from being prolonged when disease got worse”
- But - no mention of wishes about hand feeding & was spoon fed for years in nursing home
- Husband went to court twice stop feedings
- Judge said written directive not specific enough
- Finally died 2017 age 64
Recently, callers present with new diagnosis & different fears

• Historically most callers to EOLCNY had advanced cancer or ALS
• More recently, patients & families call because of diagnosis of early Alzheimer's or another form of dementia
• Some have searing memories of slow & de-humanizing dementia death of loved one & strong family/genetic pre-disposition
• For others who called, it was already too late
Hannah’s daughter called

- We stood at foot of her bed - her daughter asked me “What did I do wrong?”
- Before AZD diagnosis they met with family attorney to complete adv dir – no consideration of future dementia or hand feeding
- Hannah is now 99; 16 yrs earlier diagnosed with Alzheimer’s (or some other dementia)
- She has been in diapers for 9 yrs in hospital bed in her living room
- She no longer speaks, or moves purposefully; she does not recognize her only child or long time care givers

Nobody knew to ask about hand feeding - many still don’t

- Hannah spoon fed 3 x day by very patient aides – each ‘meal’ takes more than an hour
- She reflexively opens her mouth when spoon brought to its side...like a baby bird
- She was deemed ‘terminal’ over 2 years ago
- Hospice says she must continue to be spoon fed until she ‘forgets’ how to swallow
- They can’t predict when that will occur
Further West coast developments

- 2017 EOLWA developed “Instructions for Oral Feeding & Drinking”
- Form stated when dementia is ‘advanced’ - oral feeding to be limited to ‘comfort-focused’
- Assisted feedings provided only while patient seems to enjoy or willingly participates in being fed
- Received with much enthusiasm in WA...

In NY, we thought we could/should go further

- Based on needs/requests EOLCNY patients newly diagnosed with dementia & their families
- Some wanted more options than limiting oral intake to ‘comfort feeding’
- Greatest fear was having to live thru final stages advanced dementia...for months or years
- While decisionally capable COULD stop all oral intake by VSED to hastened death but
- VERY challenging absent terminal illness
EOLCNY Dementia Directive

- Two purposes:
  - 1st to document pt’s wishes about limiting assisted oral feedings when dementia becomes advanced
  - 2nd to ensure appointed health care agent is empowered to implement those choices when patient suffers from advanced dementia
- Does not replace but *augments* other completed directives or instructions (must have appointed a health care agent/proxy!)
- + instructions re WHEN to begin limiting oral intake!

WHEN to implement dementia feeding limitations

3 Triggering clinical criteria for dementia directive:

1. Health care agent consults w PCP & agree patient **now in ‘advanced’ stage of dementia (stages 6-7 on Functional Assessment Staging Test)** symptoms include: inability to speak comprehensively, ambulate, recognize family or be continent
   And
2. Patient unable to make health care decisions
   And
3. Unable to feed self
### Two Options to limit assisted oral feeding when dementia advanced

- **Option A:** Refuses all life-prolonging measures including CPR & **all nutrition & hydration** (N&H) whether provided medically or by assisted oral feeding AND
  - Specifically - refuses oral feeding *even if* mouth opens when spoon touches corner
  - Requests provision of excellent comfort care & symptom management with palliative or hospice care once feedings stopped

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### 2nd option limiting assisted feeding

- **Option B:** Refuses all life-prolonging measures including CPR & **medically provided** N&H & **limits** oral feeding to comfort focused - e.g:
  - Feedings provided only while pt shows enjoyment or positive anticipation re eating
  - Only given foods & fluids seems to enjoy
  - Feedings stopped once pt no longer appears interested or begins to cough or choke
  - Pt not to be coerced or cajoled into eating
  - Once feeding stopped – access to comfort measures & medications with palliative or hospice care
Further IMPORTANT instructions

• Once dementia directive completed, discuss with: PCP, health care agent, family members, attorney & all other ‘stakeholders’ who care about patient
• Give copies of directive to all of above
• Patient should make videotape of personal values & reasons why directive completed & give copy to all of above
• Remind all you are trusting them to NOT disregard your wishes b/c you ‘appear’ comfortable or have ‘adequate’ quality of life

Long term care considerations

• As dementia becomes advanced, long term care placement often becomes necessary
• In anticipation of such transfer - patients & families should explore whether LTC administrators will honor dementia directive BEFORE entering facility
• In-service education within LTC facilities will be necessary – particular among CNA’s who provide most care & often know patients best (video very important for them)
• We anticipate judicial review
The Compliance Perspective

• Eating & Drinking and the Law
• How did we get here?
• Where are we going?

Think about 1914
Think about 1914

Benjamin Cardozo:

"Every human being of adult years and sound mind has a right to determine what shall be done with his own body."

_Schloendorff v. Society of New York Hospital_
211 N. Y. 125, 129-130, 105 N. E. 92, 93 (1914)
Delio v Westchester

View New York Official Reports version

129 A.D.2d 1
Supreme Court, Appellate Division, Second Department, New York.

In the Matter of Julianne DELIO, etc., Appellant,
v.
WESTCHESTER COUNTY MEDICAL CENTER, et al., Respondents.

June 1, 1987.

Synopsis
Wife of 33-year-old patient in chronic vegetative state with no hope of recovery petitioned to terminate patient's care. The Supreme Court, Westchester County, 134 Misc.2d 106, 510 N.Y.S.2d 415, Cerrato, J., denied the petition, and wife appealed. The Supreme Court, Appellate Division, Thompson, J., held that wife, as conservator of patient, was entitled to act in accordance with prior clearly expressed wishes of patient and have use of feeding and hydration tubes discontinued.

Judgment reversed; petition granted.

O’Connor v. Westchester

View New York Official Reports version

72 N.Y.2d 517
Court of Appeals of New York.

In the Matter of WESTCHESTER COUNTY MEDICAL CENTER, on
Behalf of Mary O’CONNOR, Appellant.
Helen A. Hall et al., Respondents.


Synopsis
Hospital sought order to permit it to administer nasogastric feeding to incompetent patient. The Supreme Court, Westchester County, Ciabatella, J., denied hospital's application, and hospital appealed. The Supreme Court, Appellate Division, Mangano, J.P., 135 App.Div.2d 344, 532 N.Y.S.2d 133, affirmed, and hospital appealed by permission. The Court of Appeals, Wachtler, C.J., held that hospital was authorized to insert nasogastric feeding tube into allegedly, mentally incompetent patient who was unable to obtain food and drink without medical assistance, in that there was no clear and convincing proof that patient had made firm and settled commitment, while competent, to decline assistance under instant circumstances.

Reversed.
N.Y.S Proxy Law

McKinney’s Public Health Law § 2982

§ 2982. Rights and duties of agent

Currentness

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.

N.Y.S Proxy Law

...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.
NYS DOH Guidance

- The Health Care Proxy Law
- A Guidebook For Health Care Professionals
  - January 1991
  - Prepared By:
    - The New York State Department of Health
    - The New York State Task Force on Life and the Law
    - In Consultation With:
      - Association of the Bar of the City of New York Greater New York Hospital Association Hospital Association of New York State Medical Society of the State of New York New York Academy of Medicine New York State Nurses Association

Guidance Continued:

- Q: Must evidence of the patient’s wishes about artificial nutrition and hydration be written on the proxy form?
  - No. There is no requirement that this evidence be written on the proxy form or elsewhere. The agent’s knowledge can be based on prior oral statements by the patient and knowledge of the patient’s religious, moral and personal beliefs about health care.

- Q: What if the agent’s decision appears to conflict with written instructions by the patient on the proxy form or elsewhere?
  - Health care professionals should honor the agent’s decision if they believe the agent is not violating the patient’s wishes, but is interpreting the patient’s wishes in good faith in light of available medical information and circumstances.
Federal influence on End of life care and feeding:

42 CFR 488.301

Title 42 Part 488 → Subpart E → §488.301

Title 42 → Chapter IV → Subchapter G → Part 488 → Subpart E → §488.301


Federal Regulation Definitions:

§488.301 Definitions.
As used in this subpart—

***

Abuse is the willful infliction of injury, unreasonable confinement, intimidation, or punishment with resulting physical harm, pain or mental anguish. Abuse also includes the deprivation by an individual, including a caretaker, of goods or services that are necessary to attain or maintain physical, mental, and psychosocial well-being. Instances of abuse of all residents, irrespective of any mental or physical condition, cause physical harm, pain or mental anguish. It includes verbal abuse, sexual abuse, physical abuse, and mental abuse including abuse facilitated or enabled through the use of technology. Willful, as used in this definition of abuse, means the individual must have acted deliberately, not that the individual must have intended to inflict injury or harm.

***

Immediate jeopardy means a situation in which the provider’s noncompliance with one or more requirements of participation has caused, or is likely to cause, serious injury, harm, impairment, or death to a resident.

***

Neglect is the failure of the facility, its employees or service providers to provide goods and services to a resident that are necessary to avoid physical harm, pain, mental anguish, or emotional distress.
State Operations Manual
Appendix Q - Guidelines for Determining Immediate Jeopardy
(Rev. 102, Issued: 02-14-14)

<table>
<thead>
<tr>
<th>Triggers</th>
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<tbody>
<tr>
<td>D Failure to protect from undetected adverse medication consequences and/or failure to provide medications as prescribed.</td>
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<tr>
<td>1. Administration of medication to an individual with a known history of allergic reaction to that medication;</td>
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<tr>
<td>2. Lack of monitoring and identification of potential serious drug interaction, side effects, and adverse reactions;</td>
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<tr>
<td>3. Administration of contraindicated medications;</td>
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<td>4. Pattern of repeated medication errors without intervention;</td>
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<td>5. Lack of diabetic monitoring reaching or likely to result in serious hypoglycemic or hyperglycemic reaction; or</td>
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<td>E Failure to provide adequate nutrition and hydration to support and maintain health.</td>
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<tr>
<td>1. Food supply inadequate to meet the nutritional needs of the individual;</td>
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<tr>
<td>2. Failure to provide adequate nutrition and hydration resulting in malnutrition; e.g., severe weight loss, abnormal laboratory values;</td>
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<tr>
<td>3. Withholding nutrition and hydration without advance directive; or</td>
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<tr>
<td>4. Lack of potable water supply.</td>
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<tr>
<td>F Failure to protect from widespread nosocomial infections; e.g., failure to practice standard precautions, failure</td>
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<tr>
<td>1. Pervasive improper handling of body fluids or substances from an individual with an infectious disease;</td>
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<tr>
<td>2. High number of infections or contagious diseases without appropriate reporting, investigation and care;</td>
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<tr>
<td>3. Pattern of ineffective infection control precautions; or</td>
</tr>
<tr>
<td>4. High number of nosocomial infections caused by cross contamination from staff and/or equipment supplies.</td>
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State Operations Manual:

Example Case #2 (Continued): (Refer to B - Investigation) During the investigation, the surveyor finds that the chart does not include a copy of the patient’s advance directive. The progress note does not contain any documentation of the patient ever stating a wish to have nutrition and hydration withdrawn at the end of life. The patient has a diagnosis of advance dementia with a documented history of refusal to eat in a long-term care facility. The patient had been admitted because of continued weight loss and dehydration related to the refusal to eat or drink. The patient has a daughter who actively
Borenstein decision in New York:

View New York Official Reports version
8 Misc.3d 461
Supreme Court, Queens County, New York.

Rose BORENSTEIN, as proposed Special Needs Guardian and guardian
ad litem for her disabled sister, Lee Kahan, an incapacitated person,
Petitioner,
v.
Joan SIMONSON, as Lee Kahan’s health care agent and West Lawrence
Care Center, Respondents.

March 30, 2005.

Synopsis
Background: Sister of incapacitated patient with advanced Alzheimer's disease petitioned
to have percutaneous endoscopic gastrostomy (PEG) tube inserted to provide hydration
and nutrition, and to void patient's prior health care proxy held by patient's daughter, or in
the alternative, to enjoin daughter from interfering with future health care decisions
affecting patient's artificial hydration and nutrition.

Borenstein decision:

Synopsis
Sister of incapacitated patient with advanced Alzheimer's disease petitioned to have percutaneous
endoscopic gastrostomy (PEG) tube inserted to provide hydration and nutrition, and to void patient's prior
health care proxy held by patient's daughter, or in the alternative, to enjoin daughter from interfering with
future health care decisions affecting patient's artificial hydration and nutrition.
Borenstein decision:

Holdings: Following daughter’s withdrawal of objection to insertion of PEG tube, the Supreme Court, Queens County, Martin E. Ritholtz, J., held that:
1 proxy did not give patient’s daughter, as the proxy holder, authority to make decisions about artificial nutrition and hydration for patient;
2 revocation was not warranted on grounds of mental incompetence; and
3 daughter’s reluctance to insert PEG tube was not evidence of bad faith warranting revocation of proxy.

Institutional reactions:

If this is the right thing to do for patients, why are nursing homes and hospitals so resistant?
3 indicted in death of nursing home patient

By EILEEN McCULLY
STAFT WRITER

A Putnam County grand jury has indicted three women in the case of a female patient who died after wandering outside of Hilty Home, a Pandora nursing home, in January.

Rachel K. Flower, 26, and Deonti M. Feldt, 20, both of Pandora, were each charged with involuntary manslaughter, a third-degree felony; forgery, a fifth-degree felony; gross patient neglect, a first-degree misdemeanor; and patient neglect, a second-degree misdemeanor.

Megan R. Spohn, 21, of Columbus Grove, was charged with forgery, a fifth-degree felony; gross patient neglect, a first-degree misdemeanor; and patient neglect, a second-degree misdemeanor.

The indictment does not specify what role the women played in the death.

An arraignment for the women is scheduled May 14.

Phyllis J. Campbell, 76, formerly of Findlay, died Jan. 7 outside the Pandora nursing home, which is operated by Meamore Home Communities of Ohio.
Where do we go from here?

Patients must appoint an agent who knows, **and will follow**, the patient’s wishes regarding oral feeding.

And leave behind clear written instructions that describe their values and preferences.

- Reimbursement considerations
  - Medicaid
    - Medicare
  - Commercial insurers
What could possibly go wrong?

Regulations state, "(b) a plan of care is established for each patient based on a professional assessment of the patient’s needs and includes pertinent diagnosis, prognosis, need for palliative care, mental status, frequency of each service to be provided, medications, treatments, diet regimens, functional limitations and rehabilitation potential."

10 NYCRR Section 766.3(b)
Back to the State Operations Manual:

State Operations Manual
Appendix Q - Guidelines for Determining
Immediate Jeopardy
(Rev. 102, Issued: 02-14-14)

E Failure to provide adequate nutrition and hydration to support and maintain health.

Food supply inadequate to meet the nutritional needs of the individual;
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3. Withholding nutrition and hydration without advance directive; or
4. Lack of potable water supply.

And Remember:

More and More,

Every Day,

Compliance is about Quality
In Summary....

You can get paid for not force feeding your patients if:

Patient expressed their wishes in writing, while capacitated to make decisions about eating and drinking.

Patient has appointed a proxy to be their advocate.

*All* required documentation supports the conclusion that care providers are legally prohibited from providing unwanted feeding.

Start reading up on the topic,

Starting with:
Final thoughts for Compliance Officers:
  • Patient MUST have an appointed health care agent to advocate for limiting oral feedings!!
  • Re need for ongoing counseling? Limiting oral feedings from an incompetent loved one may be a hard for family to support &/or implement; should be discussed regularly
What to do next, ask for help:

- We welcome your feedback, stories & experiences about refusal of oral feeding.
- Contact:
  - Judy Schwarz: judy@endoflifechoicesny.org
  - David N. Hoffman: dnh2101@Columbia.edu
  - For dementia advance directive: www.endoflifechoicesny.org

BIOETHICS
Master of Science & Certificate Programs

Questions, Concerns?

David N. Hoffman
dnh2101@Columbia.edu

http://sps.columbia.edu/bioethics
REFERENCES


DOI: 10.1002/hast.865


Schwarz, JK (in press) LESSONS FROM NEW YORK’S DEMENTIA DIRECTIVE AND APPLICATIONS TO WITHHOLDING ORAL FEEDINGS. A case study AJOB.


www.alz.org/alz-demographics/facts/figures (accessed 9/5/18)

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David’s advance directive:

- I do not want to be a potted plant.
- If I am unable to express myself and show signs of experiencing joy, I want all but pain care withheld, (including all feeding,) so that my passing can come quickly.
- Organs to the living, body to science, then to the sea.
- Smile and Breathe.

D.N.H.
Bioethics Masters Degree Programs

http://sps.columbia.edu/bioethics