O.O.I.E.
NJ Office of the Ombudsman for the Institutionalized Elderly

HCANJ
20 Hour Symposium
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Disclosure of Commercial Interests

The speakers have commercial interests in the following organization(s):
James McCracken – no commercial interest
Helaine B. Ledany -

Buckingham at Norwood
240 bed Medicare and Medicaid certified facility in NJ
New Jersey’s Office of the Ombudsman

Regional Ethics Committees:
Addressing LTC Residents Biomedical Ethics Issues

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OVERVIEW
Mission

The New Jersey Office of the Ombudsman for the Institutionalized Elderly is part of a national resident-focused advocacy program that seeks to protect the health, safety, welfare, and civil and human rights of older individuals in institutions. Staff and volunteers work with individual residents to help them address challenges they face; in addition, OOIE seeks opportunities to bring about systems change on local, state, and federal levels.
Constituents

Individuals 60 years and older living in long-term care institutions, Independent Living section of CCRC, and certain community settings.
Care Settings

Settings that our constituents live in:

- Nursing Homes
  (including state veterans’ homes)
- Assisted Living
  (including ALs, ALRs, ALPs, and CPCHs)
- Independent Living Section of CCRC
- Residential Health Care Facilities
- Boarding Homes
- State Psychiatric Hospitals
- State Developmental Centers
- Adult Medical Day Care
Roles & Responsibilities of Ombudsman
Federal Law, Older Americans Act

- Investigate and resolve complaints made by or on behalf of residents of LTCF
- Provide services to help residents protect their health, safety, welfare, and rights and to inform residents of how to obtain such services
- Represent residents’ interests before government agencies and seek administrative, legal, and other remedies to protect the health, safety, welfare, and rights of the residents;
- Conduct legislative and policy advocacy on federal, state, and local levels
Roles & Responsibilities of Ombudsman
Federal Law, Older Americans Act (cont.)

• Train and provide administrative and technical assistance to OOIE staff and volunteers

• Identify and work to resolve problems affecting large numbers of older people in LTCF or receiving LTC

• Promote the development of citizens’ organizations to advocate for quality LTC services

• Compile and analyze data relating to complaints and conditions in LTCF and LTC services
Roles & Responsibilities of Ombudsman
State Law

- Receive and investigate reports of abuse and exploitation of institutionalized elderly from “mandated reporters”

- Receive reports from residents and any other concerned people regarding the health, safety, welfare, and civil and human rights of residents

- Refer cases to appropriate regulatory and law enforcement agencies where OOIE findings require referral

- **Review certain decisions regarding withholding or withdrawing life-sustaining medical treatment.**
Roles & Responsibilities of Ombudsman
State Law End-of-Life

• New Jersey Regulations set forth in N.J.A.C 17:41-2.3

Duty to report

(a) Any person who believes that withholding or withdrawing life-sustaining treatment from an elderly, incapacitated resident of a facility would effectuate the residents wishes or would be in the resident’s best interests shall notify the Office of the contemplated action.
END OF LIFE
Ethical Decisions at End-of-Life
N.J. Supreme Court and OOIE

In *Conroy* and other cases, the court called for the Ombudsman to become involved because of:

- the vulnerability of mentally and physically impaired elderly people in institutions,
- the absence of surviving family and friends,
- the limited role physicians play in nursing homes as compared to hospitals, and
- the potential for abuse with unsupervised institutional decision-making during that time period.
Ethical Decisions at End-of-Life Ombudsman Process

As with all of the Ombudsman’s work, the primary focus of the process is to ensure that the resident’s wishes are respected. The Office works with the resident, his or her family and friends, and facility staff to identify the resident’s wishes, wherever possible.

In addition to exploring the resident’s wishes, the Office also gathers clinical information regarding the resident’s cognition, condition, and prognosis, to ensure that legal standards for withholding/withdrawing treatment are met.
Regional Ethics Committees (RECs)

- Multi-disciplinary teams, including social workers, nurses, clergy, and hospice workers

- Established to serve as a resource to residents and health care professionals of LTCF’S who face ethical dilemmas:
  - Treatment decisions
  - Health care conflicts
  - Withholding/withdrawing LST
  - Quality of life issues

- Consultation not required and recommendations not legally binding but can often resolve ethical dilemmas as close to the bedside as possible.
Confidentiality & “Informed” Consent
Requirements
One of major foundations of the Ombudsman’s resident-focused advocacy work is confidentiality. Federal and state laws provide strong protections for residents and complainants, and state law provides additional protections for witnesses.

Information about a resident cannot be disclosed unless:

- the individual /legal representative has consented; or
- a court orders disclosure.
CASE LAW
New Jersey Cases

- In re Quinlan, 70 N.J. 10 (1976)
- In re Conroy, 98 N.J. 321 (1985)
- In re Peter, 108 N.J. 365 (1987)
Claire Conroy was an 84-year old nursing home resident, unable to move from a semi-fetal position. She was severely demented, had heart disease, hypertension and diabetes and her left leg was gangrenous to the knee; she had pressure sores, couldn't speak, and had only a limited ability to swallow.
In the Matter of Claire C. Conroy (continued)

“A person who believes that withholding or withdrawing life-sustaining treatment would effectuate an incompetent patient’s wishes or would be in his ‘best interests’ should notify the Office of the Ombudsman of the contemplated action.”

“Any person who believes to the contrary, that is, who has reasonable cause to suspect that withholding or withdrawing the life-sustaining treatment would be an abuse of that patient, should also report such information to the Ombudsman”
In the Matter of Claire C. Conroy
(continued)

• Three tests for determining the Patient’s wishes:
  • **Subjective:** What the particular patient would have done if able to choose for herself;
  • **Limited Objective:** Some trustworthy evidence that the patient would have refused the treatment and burdens outweigh benefits;
  • **Objective:** Burdens outweigh the benefits and administering life-sustaining treatment would be inhumane.
In the Matter of Claire C. Conroy (continued)

• Patient’s intent can be determined from:
  • a written document or “living will”;
  • an oral directive to family, friend or provider;
  • appointment of a health care proxy;
  • reactions to medical treatment of others;
  • religious beliefs and tenets of her religion;
  • consistent pattern of conduct regarding prior decisions about own health care.
Surrogate Decision-Making Standards Under NJ Case Law

Standard to be applied for withdrawing or withholding life-sustaining treatment depends upon whether individual is in a persistent vegetative state.

- Persistent vegetative state
  - Guardian and/or family believe in their best judgment that the patient would not want the treatment
  - Attending physician agrees LST should be discontinued
  - Ethics committee verifies patient’s medical condition
The Evolving Legal Landscape

- Plaintiff (Daughter/Guardian): Can an institution terminate LSMT against the wishes of the surrogate?
- Defendant (Trinitas): Can surrogates force practitioners to provide inhumane and futile treatment?
- Court dismissed as moot (unusual circumstances make recurrence unlikely, sparse record on appeal)
- Stated that declining to resolve the issue not an end to the debate but called for thoughtful consideration by executive and legislative branches and development of policies
Evaluation of Preferences

- Surrogate look to previously competent persons’
  - Written documents
  - Oral directives
  - Reactions to medical treatment
  - Religious beliefs
  - Prior statements

- Probative value of prior actions or statements assessed based
  - Remoteness
  - Consistency
  - Thoughtfulness
  - Specificity of statements or actions
  - Maturity of person at the time of the statement or actions
Surrogates

- No need for guardian if there are close and caring family members or the patient left clear and convincing evidence of surrogate to make medical decisions (e.g., Advance Directive).
- Close family members are best suited to make substituted judgments for incapacitated patients.
- If there are no close family members or proxy, then a guardian must be appointed and comply with the procedural requirements.
Right to Withhold or Withdraw LST

- Basis of EOL decision-making: (1) common law right to self-determination & (2) federal and state constitutional right of privacy

- Doctrine of informed consent developed to protect right to self-determination in the medical context

- Logically flows that an individual has a right to informed refusal.

- Person retains these rights even when no capacity to assert the right or appreciate its affect.

- Balancing tests discussed in the cases are unnecessary if the individual has clearly and convincingly indicated a preference regarding life-sustaining treatment – the right to self-determination overrides the objective standards.
ETHICS
What is Ethics?

• Ethics is the study of the rational process for determining the best course of action in the face of conflicting choices
• Aims to transcend diverse moral traditions in response to conflicting values and beliefs
• What is right conduct and why?
• There is no single accepted code of behavior
Theory of Ethics Principlism

- Autonomy - Personal rule of self
  - Power over one’s own destiny
  - Consistent with life lived
- Beneficence - To do good
  - To remove harm
  - To prevent harm
- Nonmaleficence - Do no harm
  - Hippocratic Oath
- Justice - Impartiality and consistence
  - treat equal cases equally
  - treat unequal cases unequally
Case Consultation - How Does it Work?

- Case Consultations are resident centered meeting of key stakeholders.
- Referral from Ombudsman Office or Facility outreach
- Review preliminary information
  - Pertinent medical information
  - Overview of resident’s daily life and decision making capacity
  - Presence of Advance Directive
  - Circumstances contributing to dilemma
  - Dispute resolution interventions thus far
- Convene Case Consultation Panel in timely manner
- On-Site Consultation
- Recommendation – written summary and report
POLST
What does POLST address?

New Jersey Physicians Orders for Life Sustaining Treatment

- Goals of Care
- Medical Interventions
- Artificially Administered Fluids and Nutrition
- CPR
- Airway Management
# POLST FORM

**HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTHCARE PROFESSIONALS AS NECESSARY**

**NEW JERSEY PRACTITIONER ORDERS FOR LIFE-SUSTAINING TREATMENT (POLST)**

Follow these orders. Notify physician/ARN. The Medical Orders Sheet is based on the current medical condition of the person referred to below and the wishes stated verbally or in a written advance directive. Any section not completed implies full treatment for that section. Everyone will be treated with dignity and respect.

### Person Name (last, first, middle) Date of Birth

#### A. GOALS OF CARE

**Goals for care**

- [ ] Full treatment. Use of appropriate medical and surgical interventions as indicated to support life. If in a nursing facility, transfer to hospital if indicated. See section B for resuscitation status.
- [ ] Limited treatment. Use appropriate medical treatment such as antibiotics and IV fluids as indicated. May use non-invasive positive pressure ventilation. Generally will intervene only if comfort needs cannot be met.
- [ ] Transfer to hospital for medical interventions.
- [ ] Transfer to hospital only if comfort needs cannot be meet in current location.

**Additional Orders:**

#### B. MEDICAL INTERVENTIONS

Person has no pulse and/or is not breathing:

- [ ] Full treatment. Use of appropriate medical and surgical interventions as indicated to support life. If in a nursing facility, transfer to hospital if indicated. See section B for resuscitation status.
- [ ] Limited treatment. Use appropriate medical treatment such as antibiotics and IV fluids as indicated. May use non-invasive positive pressure ventilation. Generally will intervene only if comfort needs cannot be met.
- [ ] Transfer to hospital for medical interventions.
- [ ] Transfer to hospital only if comfort needs cannot be met in current location.

**Additional Orders:**

#### C. ARTIFICIALLY ADMINISTERED FLUIDS AND NUTRITION

- [ ] Intravenous fluids by route if feasible and desired.
- [ ] No intravenous fluids.

#### D. CARDIOPULMONARY RESUSCITATION (CPR)

**Cardiopulmonary Resuscitation (CPR)**

- [ ] Attempt resuscitation/CPR
- [ ] Do not attempt resuscitation/DNR

**Airway Management**

- [ ] Insert endotracheal tube as needed
- [ ] Do not intubate: use O2, no treatment to relieve airway obstruction, medications for comfort

#### E. PRINT NAME OF SURROGATE DECISION MAKER, DATED BELOW, TO MODIFY OR CANCEL THE NJ POLST ORDERS IN CONSULTATION WITH MY HEALING PHYSICIAN/ARN.

- [ ] Yes
- [ ] No

**Print Name of Surrogate:**

Date:  

**Print Phone Number:**

#### F. SIGNATURES

- [ ] Patient Name & Address
- [ ] Healthcare Proxy/Power of Attorney
- [ ] Healthcare Proxy/Power of Attorney
- [ ] Parent of Minor
- [ ] Other Surrogate

**Has the person named above made an anatomical gift:**

- [ ] Yes
- [ ] No
- [ ] Unknown

**These orders are consistent with the person's medical condition, known preferences and last known instructions:**

**Please use this form to summarize the information:**

**Prepared by:**  

**Doctor/Physician Name:**  

**Date:**  

**Phone Number:**  

**Send original form with person whenever transferred.**
Possible Candidates for POLST

- Anyone expected to die or lose Decision Making Capacity within next year
- Frail elderly and terminally ill
- Long-term residents in LTC facility
- People who are chronically ill and have multiple contacts with health care system
- Anyone choosing Do Not Resuscitate and Allow Natural Death

Not indicated for healthy person for “what if”
ISSUES/CONCERNS
Identified Issues and Concerns of LTC community

- Advance Directives
- POLST
- DNR / Do Not Hospitalize
- End of life care - Palliative Care - Hospice
- Withholding/Withdrawing Life Sustaining Medical Treatment (LSMT) Ex. Feeding-tubes & Ventilation weaning.
- Decision making capacity (differentiate between competency and capacity) Ex. Legally Dementia not same as Incapacitated.
- Staff Education
- Pain Management
- “Everyday Ethics” (hoarding, nanny cams, sexual identity)
How to Avoid Ethical Dilemmas in LTC

- Resident centered care comes first
- Communication
- Advance Directives
- Education / Networking
Key words at End of Life

- Autonomy
- In Context
- Goals of Care
- Goals of Treatment
- Communication