“NJSNA supports education of nurses which enables them to:”

“Understand the Federal and State requirements for Advance Directives”

“Be prepared to talk to the client and family about advance directives”

N.J. S.B. 2197

“Board of Nursing shall require that a person certified as an advanced practice nurse . . . complete two credits of educational programs . . . related to end-of-life care”

Passed out of committee May 12

Must still go to Senate, House, Governor

Prudent

Required?
Not all law

End-of-Life Care in New Jersey

45 min
15 min Q&A
-- Break --
45 min
15 min Q&A

A Report of the Dartmouth Atlas Project
Compared to the average American

In last 6 months, NJ

- 30% more days in hospital
- 43% more physician visits
- 44% more days in the ICU

| Total physician visits* per decedent during the last 2 years of life | 75.6 visits | 1 of 61 |
| Medical specialist visits* per decedent during the last 2 years of life | 42.7 visits | 1 of 61 |
| Total physician visits per decedent during last 6 months of life | 41.5 visits | 1 of 61 |
| Medical Specialist visits* per decedent during the last 6 months of life | 25.9 visits | 1 of 61 |
| Percent of decedents seeing 10 or more different physicians* during the last 6 months of life | 38.7% | 1 of 61 |

Value = \frac{Quality}{Cost}

Treatment is unwanted

71%: “More important to enhance the quality of life for seriously ill patients, even if it means a shorter life.”

National Journal (Mar. 2011)

<table>
<thead>
<tr>
<th>Question and Responses(^a)</th>
<th>Public, % (n=1006)</th>
<th>Professionals, % (n=774)</th>
</tr>
</thead>
<tbody>
<tr>
<td>If doctors believe there is no hope of recovery, which would you prefer?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life-sustaining treatments should be stopped and should focus on comfort</td>
<td>72.8</td>
<td>92.6</td>
</tr>
<tr>
<td>All efforts should continue in an effort to save the patient's life</td>
<td>20.6</td>
<td>2.5</td>
</tr>
</tbody>
</table>
84% would trade length of life for quality of life

**N.J. S.B. 2199**

The current health care system in New Jersey often fails to meet the special needs of persons who are approaching the end of life by depriving them of the opportunity that they earnestly desire to spend their final months free of pain, in familiar surroundings, together with their friends and families,

instead of being tethered to tubes and other medical apparatus in an intensive care unit or other acute care hospital setting

**Harm to family**

Emotional

Economic
Harm to others
- Limited ICU beds
- ER boarding
- Antibiotic resistance
- Moral distress

Not public policy
Not rationing

Rights patients have regarding their medical treatment under New Jersey law under federal law
Rise of Bioethics

1960s
CPR
Dialysis
Mechanical ventilators

Salgo v. Stanford
(Cal. App. 1957)
Natanson v. Kline
(Kan. 1960)

"At common law, ...the logical corollary of the doctrine of informed consent is that the patient generally possesses the right not to consent, that is, to refuse treatment.”
- Cruzan v. Missouri DOH (1990)
(Rehnquist, C.J.)

Easier situation
Contemporaneous patient refusal
More common, more complicated
Patients lack capacity

Ability to understand the significant benefits, risks and alternatives to proposed health care
Ability to make and communicate a decision.

Task specific
Fluctuates over time
**Lane v. Candura**  
(Mass. 1978)

77yo Rosaria Candura  
Gangrenous right foot and leg  
Refuse consent for amputation

**In re Maynes-Turner (Fla. App. 1999)**

Doc: “Cognitively she does reasonably well. She would seem to possess the necessary knowledge that would be required for restoration.”

Doc: “She might pose significant risks for herself on the basis of those decisions that she would make.”

**DHS v. Northern**  
(Tenn. 1978)

Mary Northern 72yo  
Admitted Nashville Gen.  
Gangrene both feet  
Amputation required to save life

**Soft paternalism**  
Cognitive or volitional defect

**Hard paternalism**  
No cognitive or volitional defect  
Restrict autonomy because values
Patient not lose autonomy right
Who decides
What standards

Court-appointed “guardian”
Patient-designated “agent”
Default “proxy” “surrogate”
Advance Directives

Advance directive
Document that instructs health care providers about your care when you cannot

“Springing”

Only effective when you lack capacity


Proxy directive

“health care representative”
“durable power of attorney for health care”
“agent”

Type 1 of 3

A) CHOOSING A HEALTH CARE REPRESENTATIVE:

I hereby designate ______________________ .
of ______________________ .

(home address and telephone number of health care representative)
as my health care representative to make any and all health care decisions for me, including decisions to accept or
A proxy shall act in accord
“directive . . . decisions”
“the maker’s . . . wishes”
“maker’s best interests”

Initial ONE of the following two statements with which you agree:

1. I direct that all medically appropriate measures be provided to sustain my life, regardless of my physical or mental condition.
2. There are circumstances in which I would not want my life to be prolonged by further medical treatment. In these circumstances, life-sustaining measures should not be initiated and if they have been, they should be discontinued. I recognize that this is likely to hasten my death. In the following, I specify the circumstances in which I would choose to forgo life-sustaining measures.

C) SPECIFIC DIRECTIONS: Please initial the statement below which best expresses your wishes.

___ My health care representative is authorized to direct that artificially provided fluids and nutrition, such as by feeding tube or intravenous infusion, be withheld or withdrawn.

___ My health care representative does not have this authority, and I direct that artificially provided fluids and nutrition be provided to preserve my life, to the extent medically appropriate.

(If you have any additional specific instructions concerning your care you may use the space below or attach an additional statement.)

Type 2 of 3
Instructional directive
“living will”

Type 3 of 3
Combined directive
Both proxy
And Instructional
Review
Decade
Death (family member)
Divorce
Diagnosis (new)
Decline (ADL)

Compliance:
Key sources

TJC Accreditation standards
Medicare COPs
NJ Advance Directives for Health Care Act

TJC
Patient Rights
RI.01.01.05

Patient Self-Determination Act (PSDA)

When
After Cruzan (June 1990)
Sen. John Danforth (Mo.)
**What**

Agnostic as to substantive rights

Assure compliance with state law

Promote ACP

---

**Who**

Facilities receiving Medicare reimbursement

Centers for Medicare & Medicare Services

Agency (inside DHHS)

Implements PSDA with conditions of participation (COP)

---

COPs apply to all patients in facility

Not just the Medicare patients
Assure New Jerseyans get rights under New Jersey law

- Notify / inform
- Document
- Respect
- Education

Mirrored in licensure code

- e.g. home health
- N.J.A.C. 8:42-6.3

On admission

Determine if patient has AD

If yes ➔
  - Get it
  - Place in chart

If no ➔
  - Give assistance on request
  - Give information about right to accept, refuse
Give information
In way patient understand
Account for age, vision, literacy

Documentation
P sign & acknowledge

After admission

Give option to review, revise AD
Honor AD
Unless conscience objection per state law
Unless other exception per state law
Do not make access to care depend on whether have AD

Respect AD – or else
TJC
CMS
State discipline
Battery
Informed consent
IIED

Education

Staff
To ensure compliance

Community
To ensure reflection
To ensure documentation
Policies & procedures

Verbal AD
When operative
Objections
Revocation

The way things are supposed to work

Too limited
EOL care discussion

EOL discussion
less aggressive medicine
### Discussed EOL Care Preferences With Physician

<table>
<thead>
<tr>
<th>Variable</th>
<th>Yes (n=70)</th>
<th>No (n=70)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical care received during the last week of life, No. (%)*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intensive care unit stay</td>
<td>2 (2.7)</td>
<td>10 (14.3)</td>
</tr>
<tr>
<td>Ventilator use</td>
<td>1 (1.3)</td>
<td>10 (14.3)</td>
</tr>
<tr>
<td>Resuscitation</td>
<td>1 (1.3)</td>
<td>6 (8.6)</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>4 (5.3)</td>
<td>7 (10.0)</td>
</tr>
<tr>
<td>Inpatient hospice used</td>
<td>8 (10.7)</td>
<td>5 (7.1)</td>
</tr>
<tr>
<td>Inpatient hospice stay ≥1 wk</td>
<td>4 (5.3)</td>
<td>2 (2.9)</td>
</tr>
<tr>
<td>Outpatient hospice used</td>
<td>58 (77.3)</td>
<td>40 (57.1)</td>
</tr>
<tr>
<td>Outpatient hospice stay ≥1 wk</td>
<td>52 (73.9)</td>
<td>34 (46.5)</td>
</tr>
<tr>
<td>Place of death, No. (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intensive care unit</td>
<td>2 (2.9)</td>
<td>9 (13.2)</td>
</tr>
<tr>
<td>Hospital</td>
<td>16 (21.7)</td>
<td>16 (22.5)</td>
</tr>
<tr>
<td>Inpatient hospice</td>
<td>5 (7.2)</td>
<td>3 (4.4)</td>
</tr>
<tr>
<td>Home</td>
<td>47 (66.1)</td>
<td>33 (46.4)</td>
</tr>
</tbody>
</table>

### EOL discussion

- Earlier hospice referral
- Better patient QOL
- Better family bereavement

### Not happening

- Limited effectiveness
- Side effects
- Options
Benefits
Risks
Alternatives
Financial

Largey v. Rothman
Before 1988
  Professional standard
After 1988
  Material risk standard

Hargett v. Vitas

Lack of awareness

Limits of Advance Directives
Not completed
Not found
Not informed
Not clear

30% 28%

Figure 1: Few Adults in New Jersey Report Having an Advance Directive

Older residents are most likely to have a directive

Source: Rutgers Center for State Health Policy,
New Jersey Family Health Survey, 2001

Not found
65-76% of physicians whose patients have advance directives do not know they exist.

Individuals fail to make & distribute copies

- Primary agent
- Alternate agents
- Family members
- PCP
- Specialists
- Attorney
- Clergy
- Online registry

Not informed

---

**Enough**

**The Failure of the Living Will**

By Angela Faustina and Carl E. Schneider

In pursuit of the dream that patients' exercise of autonomy could extend beyond their span of competence, living wills have passed from controversy to conventional wisdom, to widely promoted policy. But the policy has not produced results, and should be abandoned.
Not clear

If ______, then ______

Trigger terms vague

“Reasonable expectation of recovery”

75% 51%

25% 10%

Plus: prognosis uncertain

Preferences vague

“No ventilator”

Ever

Even if temporary
SITUATION A

If I am in a coma or a persistent vegetative state and, in the opinion of my physician and two consultants, have no known hope of regaining awareness and higher mental functions no matter what is done, then my goals and specific wishes — if medically reasonable — for this and any additional illness would be:

Less transactional
More discussion

What makes your life worth living?
How would you like to spend your last days?
What are your spiritual beliefs that might affect treatment choices?

Please check appropriate boxes:

<table>
<thead>
<tr>
<th>1. Cardiopulmonary resuscitation (electroshocks, bags, electric shocks, and artificial breathing aid at resuscitating a person who is on the point of dying)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I want</td>
</tr>
<tr>
<td>Not applicable</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Major surgery (for example, removing the gallbladder or part of the colon)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I want</td>
</tr>
<tr>
<td>Not applicable</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. Mechanical ventilation (providing breath by machine, through a tube in the trachea)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I want</td>
</tr>
<tr>
<td>Not applicable</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4. Dialysis (cleaning the blood by machine or by fluid passed through the body)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I want</td>
</tr>
<tr>
<td>Not applicable</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5. Blood transfusions or blood products</th>
</tr>
</thead>
<tbody>
<tr>
<td>I want</td>
</tr>
<tr>
<td>Not applicable</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>6. Artificial nutrition and hydration (given through a tube in a vein or in the stomach)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I want</td>
</tr>
<tr>
<td>Not applicable</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>7. Simple diagnostic tests (for example, blood tests or X-rays)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I want</td>
</tr>
<tr>
<td>Not applicable</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>8. Antibiotics (drugs used to fight infection)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I want</td>
</tr>
<tr>
<td>Not applicable</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>9. Pain medications, even if they dull consciousness and indirectly shorten my life</th>
</tr>
</thead>
<tbody>
<tr>
<td>I want</td>
</tr>
<tr>
<td>Not applicable</td>
</tr>
</tbody>
</table>

Goals Values QOL Priorities

FIVE WISHES
by YOUR P.I.R.

The Patient Initiated Order of Treatment Escalation (P.I.O.T.E) is a unique, clinically validated, treatment planning tool that empowers patients to make informed decisions about their care.

What makes your life worth living?
How would you like to spend your last days?
What are your spiritual beliefs that might affect treatment choices?
More technology is the default
Patient must opt out

Improving advance directives

More ACP
Better documentation

Prompt Providers
1991
Enforce PSDA

Voluntary Advance Care Planning
Blumenauer
H.R. 3200
Sec. 1233

One 90-minute ACP
Nine 10-minute patient visits

RED FLAG
THIS PRODUCT IS TOXIC

OBAMA CARE
SENIORS CHECK IN...
BUT THEY DON'T CHECK OUT!
PPACA silent on ACP. But does cover **annual wellness visits**.

Section 4103

DHHS: “Notice of Proposed Rulemaking: Physician Fee Schedule” (July 2010)

**Final Rule (Nov. 2010)**

Defined “VACP” as element of annual wellness visit

**Politifact.com**

*Lie of the Year:*

“Death Panels”

A **“quiet”** victory

“The longer this goes **unnoticed**, the better our chances of keeping it.”

Jan. 2011: Rescind VACP

“We did not have an opportunity to consider . . . the wide range of views . . . held by a broad range of stakeholders”
(1) In general.—Section 1861(w) of the Social Security Act (42 U.S.C. 1395x(w)) is amended—

(d) by adding at the end the following new paragraph:

“(3) For purposes of paragraph (1), the term ‘end-of-life planning’ means verbal or written information regarding—

(A) an individual’s ability to prepare an advance directive in the case that an injury or illness causes the individual to be unable to make health care decisions; and

(B) whether or not the physician is willing to follow the individual’s wishes as expressed in an advance directive.”.
Advance directive
Lower premiums

Content agnostic
Make AD available

Registries
- Organ donation

Sara’s Law
- April 2011
- Effective late 2012
- NOKR

POLST
- Physician Order Life Sustaining Treatment

POLST
- Practitioner Order Life Sustaining Treatment
<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>POST</td>
<td>Physician Order for Scope of Treatment</td>
</tr>
<tr>
<td>MOST</td>
<td>Medical . . .</td>
</tr>
<tr>
<td>COLST</td>
<td>Clinician . . .</td>
</tr>
<tr>
<td>MOLST</td>
<td>Medical . . .</td>
</tr>
</tbody>
</table>

**What is POLST**

POLST supplements AD

It does not replace it

<table>
<thead>
<tr>
<th>Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Terminally ill</td>
</tr>
<tr>
<td>Chronic progressive illness</td>
</tr>
<tr>
<td>Frailty</td>
</tr>
<tr>
<td>For those in last year of life</td>
</tr>
<tr>
<td>NJ &lt; 5 year</td>
</tr>
<tr>
<td>Others who want to define care</td>
</tr>
</tbody>
</table>
### Differences between POLST and Advance Directives

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>POLST Paradigm</th>
<th>Advance Directive</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population</td>
<td>Advanced progressive chronic conditions</td>
<td>All adults</td>
</tr>
<tr>
<td>Timeframe</td>
<td>Current care</td>
<td>Future care</td>
</tr>
<tr>
<td>Where completed</td>
<td>In medical setting</td>
<td>In any setting</td>
</tr>
<tr>
<td>Resulting product</td>
<td>Medical orders (POLST)</td>
<td>Advance directive</td>
</tr>
<tr>
<td>Surrogate role</td>
<td>Can do if patient lacks capacity</td>
<td>Cannot do</td>
</tr>
<tr>
<td>Portability</td>
<td>Provider responsibility</td>
<td>Patient/family responsibility</td>
</tr>
<tr>
<td>Periodic review</td>
<td>Provider responsibility</td>
<td>Patient/family responsibility</td>
</tr>
</tbody>
</table>
Order for LST

C
Check One

ARTIFICIALLY ADMINISTERED NUTRITION AND HYDRATION:
Always offer food by mouth if feasible and desired.
No artificial nutrition by tube:
Long-term artificial nutrition by tube:
Defined trial period of artificial nutrition by tube:
Additional Orders ________________________________

D
Check One

CARDIOPULMONARY RESUSCITATION (CPR):
Person has no pulse and/or is not breathing
Do Not Attempt Resuscitation/DAAR
Attempt Resuscitation/CPR
Additional Orders ________________________________

A

GOALS OF CARE (See reverse for instructions. This section does not constitute a medical order.)

GENDER

B

MEDICAL INTERVENTIONS:
Person has pulse and/or is breathing

Life-Sustaining Care
Use all medical and surgical interventions as indicated to support life. If in a nursing facility, transfer to hospital if indicated. See below for code status

Unlimited Additional Interventions
Use medical treatment, including anesthetics and IV fluids as indicated. Do not resuscitate. May use non-invasive positive airway pressure. Generally avoid invasive care.

In a Nursing Facility, transfer to hospital for medical interventions.

In a Nursing Facility, Do Not Transfer to hospital for medical interventions. May transfer only if comfort needs cannot be met in current location.

Palliative Care Only (comfort care only): Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction, and manual removal of oropharyngeal obstruction as needed for comfort. Antibiotics only to control infection. Transfer if comfort needs cannot be met in current location.

Additional Orders ________________________________

Lifesustaining Treatments Received (n = 1,606)*

Type of treatment
Polyst for comfort only
Polyst for comfort and life sustaining treatment
Polyst for limited interventions
Full Traditional DNR
Full Traditional

*Adapted with permission of author, Addicks and colleagues. The authors acknowledge the contributions of P. Anglim, S. W. Tolle, and W. L. Smith.
†This life-sustaining treatment is by definition hospitalization/OSHS and may include hospice, nursing home, home health, and skilled nursing facility.

Susan E. Hickman, PhD, Christine A. Nelson, PhD, RN, Nancy A Perrin, PhD, Alvin H Moss, MD, Bernard J Hammes, PhD, and Susan W. Tolle, MD.
70% - patient
30% - surrogate

POLST does not expire
But should be reviewed with change in patient’s condition or location

POLST can be revised or revoked at any time

POLST benefits
Closes gap between what people **want** and what they **get**

Brightly colored
Easily identified

Original MOLST is printed on **lilac** heavy card stock paper
But a **copy** has the same force as the original form

Specific detailed instructions
Easy to follow
No need to “interpret”
**Actionable orders**

More likely honored
No need to “translate”

**Portable**

Travels with the patient in **all** treatment settings

- Home
- LTC
- Hospital
- EMS

- **POLST**
  - Allows for choosing resuscitation
  - Allows for other medical treatments
  - Honored across all healthcare settings

- **Pre-Hospital DNR**
  - Can only use if choosing DNR
  - Only applies to resuscitation
  - Only honored outside the hospital

**POLST is Evidence Based**

- Major academic research in 3 POLST states: strong evidence base of efficacy of POLST in ensuring preferences are elicited, documented, honored, w/ pain and symptom management equivalent to those without POLST order

SENATE COMMITTEE SUBSTITUTE FOR
SENATE, No. 2197
STATE OF NEW JERSEY
214th LEGISLATURE
ADOPTED MAY 12, 2011

Sponsored by:
Senator M. TERESA RUIZ
District 29 (Essex and Union)
Senator LORETTA WEINBERG
District 37 (Bergen)

PA - implementing 2011
DE - implementing 2011
MD - implementing 2011

7/19/2010 Introduced in Senate
5/12/2011 Reported from Senate HHS Committee
5/12/2011 Referred to Senate Budget and Appropriations Committee

PSO
Form
Public awareness
Training professionals