The New Advance Directives Law:

What You, Your Practice, and Your Hospital Need to Know

A Guide to Act 169 for physicians and other providers

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ELISABETH KÜBLER ROSS'
5 STAGES OF DYING

1. DENIAL
2. ANGER
3. BARGAINING
4. DEPRESSION
5. ~~ACCEPTANCE~~

LAWYERS
LAWSUITS
COURTS
POLITICIANS
STATE LEGISLATURE
THE UNITED STATES
CONGRESS... AND
ON... AND ON...

The Blade

In this presentation

- Overview of the new law
- Advance health care directives
- The physician's role in key medical determinations
- Decision makers for incompetent patients
- The decision-making process
- Compliance by health care providers

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Prior Legislation

Current law passed in 1992

Only addressed basic advance directive scenario

Last Acts Report Card Criteria:

Do state policies (and advance directive laws) support good advance care planning?

Grade 1.0 on a scale of 0 to 5: E

A lot has happened since then…

1994 - Oregon voters approve Death with Dignity Act

1995 – Physician's Orders for Life-Sustaining Treatment Program begun in Oregon

1995 – SUPPORT Study, Joann Lynn, et. al.

1996 - Fiore case (Pennsylvania)

2000 – Bill Moyers' "On Our Own Terms," PBS

2005 – Terri Schiavo

Deficits in Current Law

Patients without an AD with POA specified had no legal decision maker.

AD only applied to limited circumstances.

DNR orders not transferrable.

No provision for non-family surrogates.

POA authority unclear.

Lacked protections for disabled.

Overview of new law

Major components

- Living wills
- Health care powers of attorney and health care agents
- Health care representatives (e.g., close family member)
- Out-of-hospital DNR orders → POLST

Overview of new law

Key changes

- Health care power of attorney
- Clear rules governing decision-making for incompetent patients
- Special rules for artificial nutrition and hydration
- Protections for the disabled
- Expanded immunity protections for physicians and other health care providers

Overview of new law

Triggering events

- Incompetent *and either*
- End-stage medical condition
- Permanently unconscious

Overview of the new law

Triggering events

Incompetent: Can no longer understand, make, and communicate health care decisions

A condition in which an individual despite being provided appropriate medical information, communication supports and technical assistance, is documented by a health care provider to be unable to:

i. Understand the potential material benefits, risks and alternatives involved in a specific proposed health care decision,

ii. Make that health care decision on his own behalf, or

iii. Communicate that health care decision to any other person.

iv. The term is intended to permit individuals to be found incompetent to make some health care decisions, but competent to make others.

Overview of the new law

Triggering events

End-stage medical condition:

- Incurable and irreversible;
- in an advanced state;
- will result in death, despite medical treatment

Overview of the new law

Triggering events

Permanently unconscious: Total and irreversible loss of consciousness and capacity for interaction with the environment

Overview of new law

Life-sustaining treatment

- Merely prolongs the process of dying or maintains the patient in a permanently unconscious state
- In advance health care directive, includes artificial nutrition and hydration only if the directive specifically provides

Advance health care directives

Living wills:

Patient instructions regarding life-sustaining treatment and other end-of life care. Not in effect unless patient:

1. Is incompetent, and
2. Has an end-stage medical condition or is permanently unconscious

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Advance health care directives

Health care powers of attorney

- Appoints agent to make health care decisions for patient
- States when and what decisions agent may make
- States patient's preferences and values to guide agent's decision-making

Advance health care directives

Authority of health care agents

- May be given broad range of authority
- Authority is usually limited to when patient is incompetent
- Not restricted to end-of-life decision-making

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Advance health care directives

Combined directive

- Incorporates features of both a living will and a health care power of attorney
- Usually best option for patients
- Allows specific instructions for end-of-life care and trusted person to decide for patient in other situations

Advance health care directives

Who can make a directive?

- Adult of sound mind
- Minor of sound mind who:
  - Has graduated from high school
  - Has married, or
  - Is emancipated

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Advance health care directives

When is a directive valid?

- Written, signed and dated
- Witnessed by two adults
- Does not need to be notarized

Provider’s role in directives

Physician Support

- Encourage patients to make an advance health care directive
- Explain meaning of key terms
- Describe and explain benefits and downsides of artificial life support and other end-of-life care

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Provider's role in directives

Medical Society resources

- Give patients Medical Society's Five Steps brochure, guide and sample form, www.pamedsoc.org/advancedirectives
- Tell patients to go to www.myfamilywellness.org for more on this topic

Provider's role in directives

Medical record documentation

- Place copy in patient's medical record when provided a copy
- Document in patient's medical record when notified that patient has revoked or amended advance directive

Key medical determinations

Attending physician responsibilities

- Makes determinations that patient
  - Has lost or regained competence
  - Has an end-stage medical condition or is permanently unconscious
- Documents in patient's medical record
- Notifies patient and health care agent

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Key medical determinations

Second opinions

- No longer required by new law
- Possibly will be required by terms of advance directive
- May be helpful when there is a question

Decision Makers

Decision makers

Potential decision makers

- Patient via instructions in living will
- Health care agent appointed in health care power of attorney
- Legal guardian of the person
- Health care representative

Decision makers

Health care representatives

- Act for incompetent adult patients who have:
  - No controlling living will,
  - No health care agent, and
  - No legal guardian of the person
- Designated by patient or priority list

Decision makers

Priority list for representatives

1. Current spouse and adult child of another relationship
2. Adult child
3. Parent
4. Adult sibling
5. Adult grandchild
6. Close friend

Decision makers

Authority of health care representatives

- Generally has same broad authority as may be given to health care agent
- Life-preserving treatment exception

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Decision makers

Additional rules

- Highest priority person is not reasonably available – use person of next highest priority
- Disqualified persons – e.g. patient's treating physician

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Decision-making process

Two steps

- Collect information
- Follow decision-making criteria

Decision-making process

General criteria for decisions

1. Clearly expressed wishes (oral or written)
2. Preferences and values (including religious and moral beliefs)
3. Best interests

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Decision-making process

Best interests evaluation – goals and considerations

- Preservation of life
- Relief from suffering, and
- Preservation or restoration of functioning

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Decision-making process

Artificial nutrition and hydration

- Starting point: Assume patient would want it, unless specifically stated otherwise in writing
- Overcome presumption only if:
  - Patient ***clearly*** expressed wishes to the contrary, or
  - It is ***clear*** from patient's preferences and values that patient would not want it

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Decision-making process

Patient countermands

- Can overrule any decision if of sound mind
- Can overrule direction to withhold or withdraw life-sustaining treatment, regardless of mental or physical condition

Provider's role in decision-making

Information disclosure

- Share same information with decision maker as you'd share with patient if competent
- Obtain informed consent when required by law, e.g., surgery
- Be aware of special rules for patients with an end-stage medical condition

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Provider's role in decision-making

Special rules for patients with end-stage medical condition

- Do not limit discussions to life-sustaining measures. Also discuss curative and palliative alternatives, e.g., pain relief
- Distinguish between:
  - End-stage medical condition, and
  - Concurrent medical condition that pre-dated the end-stage condition.

Provider’s role in decision-making

Policies and procedures

- Hospitals, nursing homes, and other facilities must have policies and procedures
- Medical staffs should develop with their administration
- Give consideration to role of ethics committee and mediation processes

Provider's role in decision-making

Communicating decisions

- Before implementing a decision, advise patient of decision and who made it
- If patient countermands, make reasonable effort to advise agent or representative

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Provider compliance

General duty to comply

- Normally must comply with instructions in living will and directions from health care agents and representatives
- Extensive immunity given when act in good faith

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Provider compliance

Moral or religious objections

You may decline to withhold or withdraw treatment, provided you:

- Inform the patient or the agent or representative, and
- Assist in the transfer of the patient to another physician

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Compliance by health care providers

Special situations

- Life-preserving care
- Comfort and other supportive care
- Pregnant woman
- Disabled patients

People with disabilities often have very conflicted views of health care professionals:

They respect the knowledge and skills of health care professionals but question whether professionals de-value people they can’t fix completely.

They need care and may not be able to live well without it but often experience abandonment through refusal to treat or truncated or obstructed access to health care professionals or not being offered the same levels of care and range of options available to people without disabilities.

They know they are both heavy consumers of health care and complicated, challenging people to care for. Yet they perceive that health care professionals frequently view them as burdens and sometimes even seem to blame them for having disabilities.

Special Populations: People with Disabilities

People with disabilities often feel devalued as health care consumers:

Health care professionals sometimes address companions & attendants rather than the individual receiving care. People with disabilities want to be acknowledged and treated with respect.

Health care professionals often fail to acknowledge deep knowledge and experience of people with disabilities & their caregivers. People with disabilities know a great deal about their conditions, how they feel and what works for them.

Health care professionals often only experience people with disabilities when they are ill and fail to recognize that they lead full, rich lives when they are well. People with disabilities know about "slow codes" and other disparities in access to care and worry about "not being worth saving".

Special Populations: People with Disabilities

People with disabilities often feel devalued as health care consumers:

Health care professionals often appear to believe that "competence" is a dichotomous condition rather than recognizing and accommodating as much autonomy and individual consumer choice as possible. People with disabilities want to be empowered to make choices that effect their lives.

Health care professionals sometimes seem to value "normal" as the only meaningful outcome and to confuse chronic disability with acute reversible conditions. People with disabilities generally come to terms with who they are – they don't want to be fixed, but instead supported when possible and healed when necessary.

Health care professionals appear unaware of the many family and community contributions made by people with disabilities. People with disabilities feel they are viewed as parasites rather than participants and contributors.

Advisory committee Establishment

(a) Within 60 days of the effective date of this section, the department shall establish a committee to advise it on regulating the mandatory use of a standardized form containing orders by qualified physicians that detail the scope of medical treatment for patients' life-sustaining wishes**. By regulation, the department may require that this form accompany patients who are transferred from one regulated facility to another and may allow attending physicians to amend, continue or void the issuing physician's order or orders contained in the form to assure its conformity with the wishes of the patient or decisions of the health care agent or health care representative.**

(b) Membership.--The committee shall include representatives from the Pennsylvania Medical Society, the Joint State Government Commission's Advisory Committee on Decedents' Estates Laws and the Pennsylvania Bar Association and other interested persons at the department's discretion.

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY

Physician Orders
for Life-Sustaining Treatment (POLST)

First follow these orders, then contact physician or NP. This is a Physician Order Sheet based on the person's medical condition and wishes. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.

Last Name

First Name/ Middle Initial

Date of Birth

A (Check One)

Cardiopulmonary Resuscitation (CPR): Person has no pulse and is not breathing.

☐ Resuscitate/CPR ☐ Do Not Attempt Resuscitation (DNR/no CPR)

When not in cardiopulmonary arrest, follow orders in **B**, **C** and **D**.

B (Check One)

Medical Interventions: Person has pulse and/or is breathing.

☐ **Comfort Measures Only** Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. ***Do not transfer*** *to hospital for life-sustaining treatment.* ***Transfer*** *if comfort needs cannot be met in current location.*

☐ **Limited Additional Interventions** Includes care described above. Use medical treatment, IV fluids and cardiac monitor as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. ***Transfer*** *to hospital if indicated. Avoid intensive care.*

☐ **Full Treatment** Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. ***Transfer*** *to hospital if indicated. Includes intensive care.*

Additional Orders: ______

C (Check One)

Antibiotics

☐ No antibiotics. Use other measures to relieve symptoms.
☐ Determine use or limitation of antibiotics when infection occurs.
☐ Use antibiotics if life can be prolonged.

Additional Orders: ______

D (Check One)

Artificially Administered Nutrition: Always offer food by mouth if feasible.

☐ No artificial nutrition by tube.
☐ Defined trial period of artificial nutrition by tube.
☐ Long-term artificial nutrition by tube.

Additional Orders: ______

E

Summary of Medical Condition and Signatures

Discussed with:
☐ Patient
☐ Parent of Minor
☐ Health Care Representative
☐ Court-Appointed Guardian
☐ Other: ______

Summary of Medical Condition

Print Physician/ Nurse Practitioner Name	MD/DO/NP Phone Number	Office Use Only
Physician/ NP Signature (mandatory)	Date	

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

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Fiori Decision, 1996

The judiciary has no role to play "where there is a loving family, willing and able to assess what the patient would have decided as to his or her treatment, all necessary medical confirmations are in hand, and no one rightfully interested in the patient's treatment disputes the family decision. Those who disagree with this view and who favor court intervention in every case often cite the need for the court to protect the patient. Underlying this rationale is the philosophy that only courts can provide the necessary safeguards to assure protection of life. This is a narrow and unhealthy view. It violates the essential and traditional respect for family. It is yet another expansion of the idea that courts in our society are the repository of wisdom and the only institution available to protect human life and dignity."

(Quoting the Superior Court decision.)

In re Fiori, 543 Pa. 592, 607-608 (Pa. 1996)

Patient competence

The Act defines incompetent as follows (and essentially defines "competent" as the opposite):

A condition in which an individual despite being provided appropriate medical information, communication supports and technical assistance, is documented by a health care provider to be unable to:

i. Understand the potential material benefits, risks and alternatives involved in a specific proposed health care decision,

ii. Make that health care decision on his own behalf, or

iii. Communicate that health care decision to any other person.

iv. The term is intended to permit individuals to be found incompetent to make some health care decisions, but competent to make others.

Countermanding an AD

Regardless of the patient's mental or physical capacity, a patient may countermand the decision of a health agent that would withhold or withdraw life-sustaining treatment by personally informing the attending physician.

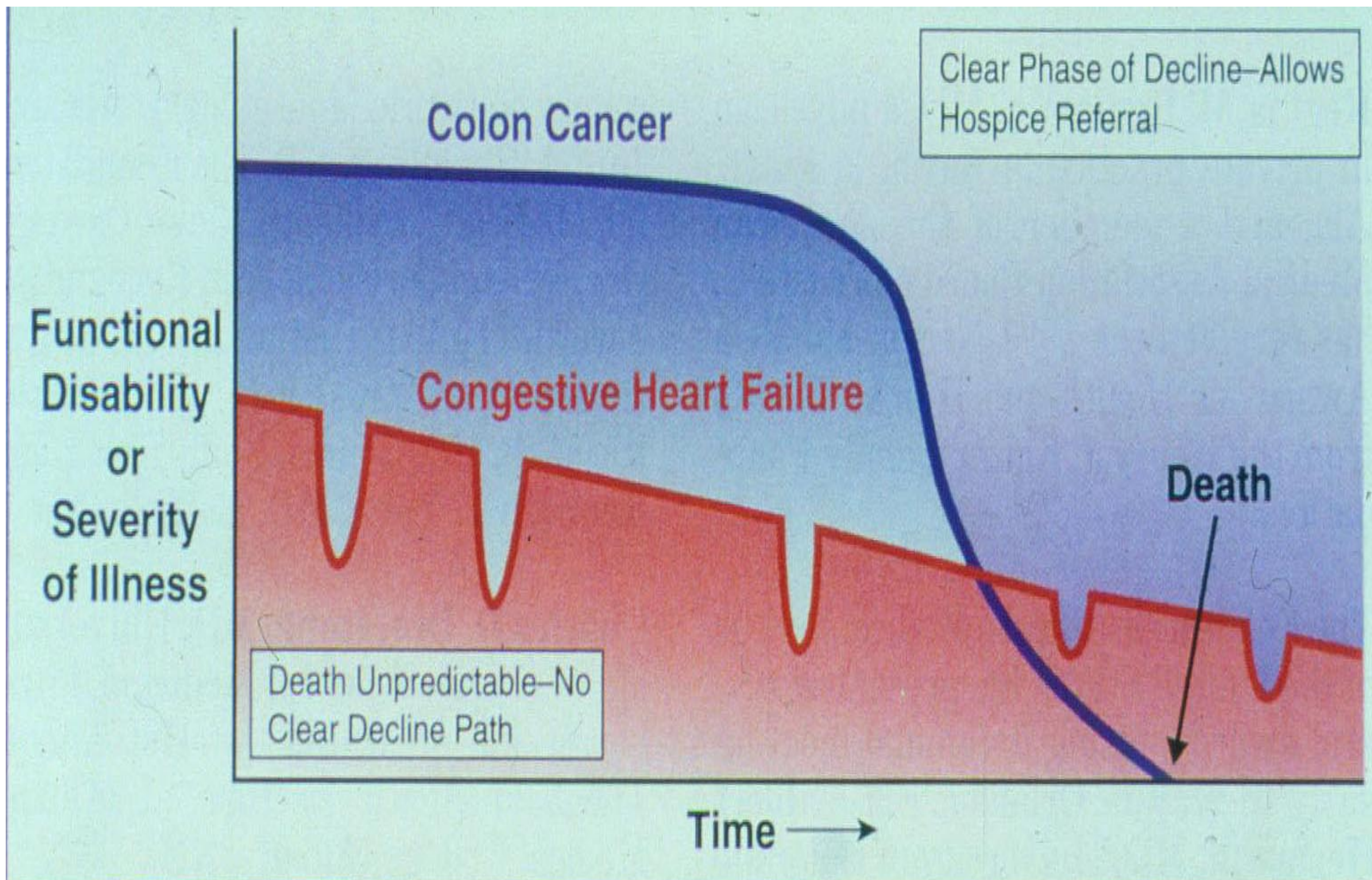
A countermand is different from a revocation of a health care power of attorney. It applies only to a specific health care decision and does not affect the authority of the agent or representative to make other health care decisions.

Immunity & Good Faith

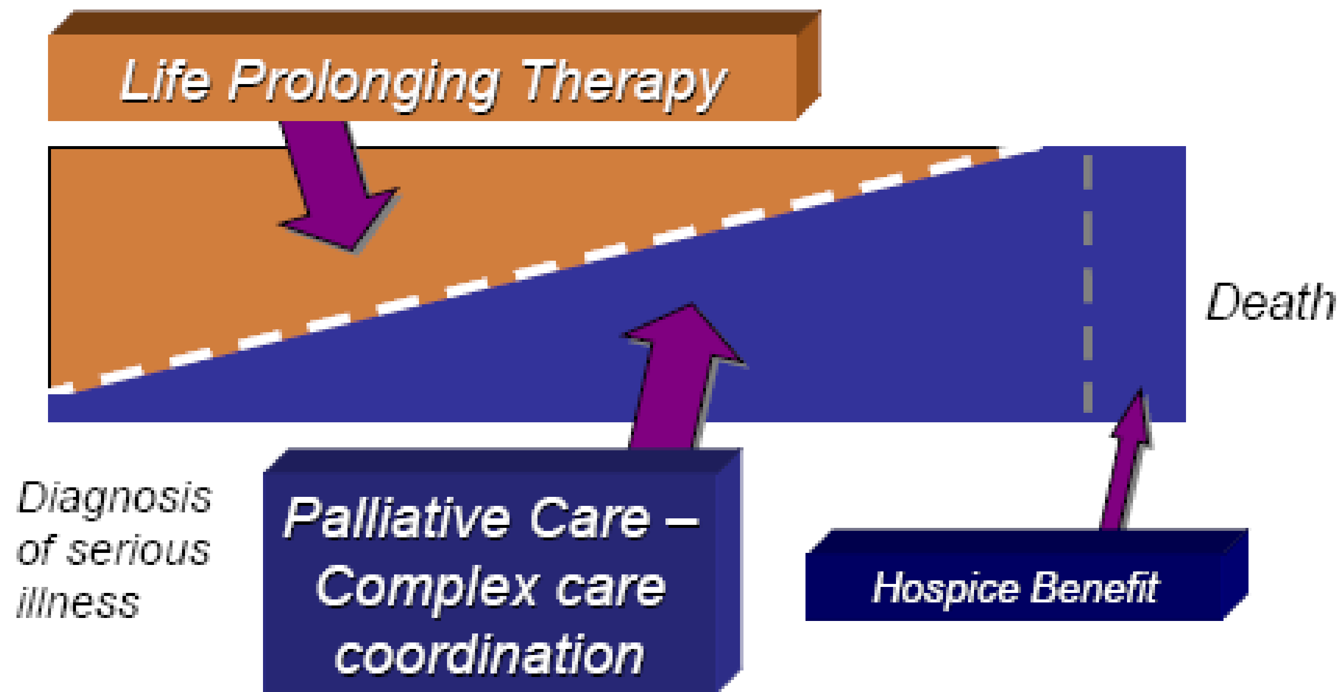
The Act includes protections for physicians and other health care providers, in recognition that they cannot be expected to research the validity of advance directives presented to them.

Health care providers are provided immunity when they comply with an advance directive on the assumption that it was valid when made and the health care provider believes in good faith that it has not been amended or revoked.

How we die



Current Paradigm



Two Types of Advance Directives

Traditional - *little or no impact on immediate care*

- **Living will**
- **Do not resuscitate order**

Actionable - *direct and relatively immediate impact on course of care*

- **POLST Paradigm form (POST, MOLST, etc.)**
- **Do not hospitalize, no feeding tube, etc.**

McAuley & Travis, Am J Hospice & Palliative Care 2003;20(5):353-359.

What Is POLST

A physician/nurse practitioner order

Can be completed by any provider but must be signed by MD, DO or NP

Complements, but does not replace, advance directives

Voluntary use, but provides consistent recongnized document.

Living Will* Compared to POLST

Living Will	**POLST**
For every adult	For the seriously ill
Requires decisions about myriad of future treatments	Decision among presented options
Clear statement of preferences	Checking of preferred boxes
Needs to be retrieved	Stays with the patient across care settings
Requires interpretation	A physician's order to be followed

**Fagerlin & Schneider. Enough: The Failure of the Living Will. Hastings Center Report 2004;34:30-42.*

The Rationale for POLST: AD Limitations

AD may not be available when needed

- **Not completed by most adults**
- **Not transferred with patient**

AD may not have prompted needed discussion and/or may not be specific enough

- **No provision for treatment in the NH or home**
- **May not cover topics of most immediate need**

AD may be overridden by a treating MD

AD does not immediately translate into MD order.

Purpose of POLST

To provide a mechanism to communicate patient preferences for end-of-life treatment across treatment settings.

POLST is for…

- Seriously ill patients*
- Terminally ill patients
- Patients with advanced frailty
- Others interested in defining their care.

** chronic, progressive disease*

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Date of Birth

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B Check One

Medical Interventions: Person has pulse and/or is breathing.

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☐ **Full Treatment** Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. ***Transfer*** *to hospital if indicated. Includes intensive care.*

Additional Orders: ______

C Check One

Antibiotics

☐ No antibiotics. Use other measures to relieve symptoms.

☐ Determine use or limitation of antibiotics when infection occurs.

☐ Use antibiotics if life can be prolonged.

Additional Orders: ______

D Check One

Artificially Administered Nutrition: Always offer food by mouth if feasible.

☐ No artificial nutrition by tube.

☐ Defined trial period of artificial nutrition by tube.

☐ Long-term artificial nutrition by tube.

Additional Orders: ______

E

Summary of Medical Condition and Signatures

Discussed with:

☐ Patient

☐ Parent of Minor

☐ Health Care Representative

☐ Court-Appointed Guardian

☐ Other: ______

Summary of Medical Condition

Print Physician/ Nurse Practitioner Name	MD/DO/NP Phone Number	Office Use Only
Physician/ NP Signature (mandatory)	Date	

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

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A

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B

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Additional Orders: ______________________________

C Check One	Antibiotics
	☐ No antibiotics. Use other measures to relieve symptoms.
	☐ Determine use or limitation of antibiotics when infection occurs.
	☐ Use antibiotics if life can be prolonged.
	Additional Orders: ______________________________

D	**Artificially Administered Nutrition:** Always offer food by mouth if feasible.
Check One	☐ No artificial nutrition by tube. ☐ Defined trial period of artificial nutrition by tube. ☐ Long-term artificial nutrition by tube.
	Additional Orders: ______________________________

E	Summary of Medical Condition and Signatures		
	Discussed with: ☐ Patient ☐ Parent of Minor ☐ Health Care Representative ☐ Court-Appointed Guardian ☐ Other: ______________	Summary of Medical Condition	
	Print Physician/ Nurse Practitioner Name	MD/DO/NP Phone Number	Office Use Only
	Physician/ NP Signature (mandatory)	Date	

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

Requirements to Make the Form Valid

Patient name

Resuscitation orders

Physician/NP signature

all other information is optional…does not require signature of patient.

POLST

Comfort measure are always provided!

Where to Keep the POLST

The front of the chart

The POLST should accompany the patient across care settings.

New Recommendation: A Two-Stage Approach to ACP

Stage I:

Encourage completion of health care power of attorney as part of health maintenance

- **Include in Social History along with seat belts**

If patient's general values are not to have life prolonged if terminally ill or in PVS, then encourage combined LW-HCPOA

- **Address cognitive impairment**

Encourage patient to indicate how much leeway they want to grant to their HCPOA representative.

Stage II: The Seriously Ill or Frail Resident

Planning for this resident includes likely contingencies for future medical treatment

- **Example: Resident with advanced COPD**
  - **BiPAP ok?**
  - **Intubation and mechanical ventilation in ICU ok?**
  - **Feeding tube ok?**
  - **Long-term mechanical ventilation if resident cannot be weaned ok?**
  - **Would hospice be preferred to above?**

Completion of POLST Paradigm form.

Essential Elements

The form may be used to either limit medical interventions or to clarify a request for all medically indicated treatments.

The form provides explicit direction about resuscitation if the patient is pulseless and apneic.

The form includes directions about other types of treatments.

Essential Elements

The form accompanies the patient, and is transferable across care settings.

The form is uniquely identifiable, standardized, uniform in color within a region/state.

There is a plan for ongoing monitoring of the program and implementation.

Take-Home Messages

Stage I of ACP should be completed with all patients

POLST Paradigm is for seriously ill patients

Use of POLST will require communication and a system to make it work

Ask "Would I be surprised…?" to identify patients for whom POLST should be completed

POLST provides a better means than AD to identify and respect patients' wishes.

Web Site Resources

www.polst.org

www.wvendoflife.org

www.eperc.mcw.edu

www.lastacts.org

www.hardchoices.com