# Rural Palliative Care Networking Group Meeting

Resolving Ethical Dilemmas in Advance Care Planning

September 14, 2017

Quality Improvement Organizations
Sharing Knowledge. Improving Health Care.
CENTERS FOR MEDICARE & MEDICAID SERVICES

Lake Superior Quality Innovation Network
MICHIGAN | MINNESOTA | WISCONSIN

## Agenda

- Welcome
- Educational Session: **Resolving Ethical Dilemmas in Advance Care Planning**
- Q&A/Sharing

# Objectives

- List several ethical dilemmas that can arise during advance care planning
- Understand the ethical responsibility of the professional care giver
- Describe procedures to be used when ethical dilemmas arise



# Presenter – Karen Peterson

# *Resolving Ethical Dilemmas in Advance Care Planning*

*Karen Peterson, Executive Director*

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## Survey Question:

Do you currently work in a facility which has an onsite (or very nearby) Ethics Team, readily available for consultation?

A. Yes, there is an Ethics Team located in my facility
B. Yes, there is an Ethics Team located in a nearby facility (less than 25 miles away)
C. No, there is an Ethics Team within my system, but not readily accessible (more than 25 miles away)
D. No, we do not have an Ethics Team

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## Def • i • ni • tion

Advance Care Planning (ACP) is a process which allows individuals the opportunity to voice their health care choices ***now*** to guide the choices about the care wanted ***later.***

A well-thought out and honored Advance Care Plan can eliminate actual harm and/or immediate jeopardy by clearly outlining the types of treatments and/or transitions preferred.

As with any decision focusing on serious illness and end-of-life care, ethical questions can arise frequently.

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# Advance Care Planning

Conversations:
- Agent
- Family members
- Other loved ones (“intentional posse”)

Documents:
- Health Care Directive (various forms)
  - Health care Power of Attorney
  - Living Will
- POLST
- Medical record

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# Advance Care Planning

ACP comes down to three basic questions:

1. Who do you trust to speak for you when you cannot?
2. Do you want life-prolonging measures (including CPR) if your healthcare team agrees your chances of survival or recuperation are extremely slim?
3. What do you want your healthcare team to know about you (spiritual, cultural, personal)?

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# Minnesota Law

**145C.03 REQUIREMENTS.**
**Subdivision 1.Legal sufficiency.**

To be legally sufficient in this state, a health care directive must:

(1) be in writing;
(2) be dated;
(3) state the principal's name;
(4) be executed by a principal with capacity to do so with the signature of the principal or with the signature of another person authorized by the principal to sign on behalf of the principal;
(5) contain verification of the principal's signature or the signature of the person authorized by the principal to sign on behalf of the principal, either by a notary public or by witnesses as provided under this chapter; and
(6) include a health care instruction, a health care power of attorney, or both.

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# Minnesota Law

**145C.11 IMMUNITIES.**
**Subdivision 2. Health Care Provider.**

(a) With respect to health care provided to a patient with a health care directive, a health care provider is not subject to criminal prosecution, civil liability, or professional disciplinary action if the health care provider acts in good faith and in accordance with applicable standards of care.

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# Minnesota Law

**145C.11 IMMUNITIES.**
**Subdivision 2. Health Care Provider.**

(b) A health care provider is not subject to criminal prosecution, civil liability, or professional disciplinary action if the health care provider relies on a health care decision made by the health care agent and the following requirements are satisfied:

(1) the health care provider believes in good faith that the decision was made by a health care agent appointed to make the decision and has no actual knowledge that the health care directive has been revoked; and

(2) the health care provider believes in good faith that the health care agent is acting in good faith.

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# Minnesota Law

**145C.11 IMMUNITIES.**
**Subdivision 2. Health Care Provider.**

(c) A health care provider who administers health care necessary to keep the principal alive, despite a health care decision of the health care agent to withhold or withdraw that treatment, is not subject to criminal prosecution, civil liability, or professional disciplinary action if that health care provider promptly took all reasonable steps to:

(1) notify the health care agent of the health care provider's unwillingness to comply;

(2) document the notification in the principal's medical record; and

(3) permit the health care agent to arrange to transfer care of the principal to another health care provider willing to comply with the decision of the health care agent.

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# *Your* State Law

**Usual differences:**

- **Witnessing requirements**
- **Agent signature/involvement**
- **Breadth of Agent authority**
  - **Location of services**
  - **Intrusive mental health treatments**
  - **Decisions post-mortem**

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## *History …*


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| | |
|---|---|
| **Karen Ann Quinlan** | 22yo; Catholic; 1976 party (drugs & ETOH after extreme dieting), collapsed @ home, 15 min w/o breathing before EMTs, parents petitioned court to remove life support after hospital refused, vent removed 1976, died 1985. **Led to development of Ethics Teams, right to end "extreme measures".** |
| **Nancy Cruzan** | 25yo, 1983 car accident (under water), family had to provide clear and convincing proof she would not want to have lived in persistent vegetative state. Died in 1990 at age of 33. **Led to recognition of individual's right to determine, started living will movement.** |
| **Teri Schiavo** | 26yo, 1990 collapse at home – cardiac arrest. 1998 husband petitioned to remove life support, parents fought it, courts supported husband, parents appealed, government involvement, 14 appeals later – husband's wish prevailed in 2005 – feeding tube removed, she died ~2 wks later. **Led to legal rights of agent/proxy.** |
| **Marlise Muñoz** | 33yo, 2013 pulmonary embolism, collapsed at home. 14 weeks pregnant so even though already declared brain dead, hospital overrode her & husband's wishes to not be kept alive. 2 months of legal battle, eventual ruling that TX law was not relevant as mother had been declared dead, also fetus was nonviable due to death of mother. **Led to discussion (continues today) of rights of mother vs fetus.** |
| **Brittany Maynard** | 29yo, terminal brain cancer, chose to move from CA to OR to have right to end own life, 2014. **Led to increased national attention (continues today) to physician aid in dying regulations.** |

## Questions of Ethics related to ACP

- Family Disagreements
- Decisions without prior discussion
- Conflicting treatment options
- Discord related to cultural, personal and/or spiritual beliefs and traditions
- Interpretation of written word
- Cost of treatment

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## Ethical principles of nursing: how do they relate to ACP?

**Autonomy**

**Beneficence**

**Nonmaleficence**

**Fidelity**

**Justice**

**Paternalism**

**Totality/Integrity**

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## Ethical principles of nursing: how do they relate to ACP?

Autonomy → Respect patients' wishes and right to self-determination and independent decision-making (even if you do not agree)

Beneficence

Nonmaleficence

Fidelity

Justice

Paternalism

Totality/Integrity

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## Ethical principles of nursing: how do they relate to ACP?

Autonomy

Beneficence → Have compassion, take positive actions to help others, and follow through on the desire to do good.

Nonmaleficence

Fidelity

Justice

Paternalism

Totality/Integrity

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## Ethical principles of nursing: how do they relate to ACP?

Autonomy

Beneficence

Nonmaleficence → Avoidance of harm or hurt.

Fidelity

Justice

Paternalism

Totality/Integrity

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## Ethical principles of nursing: how do they relate to ACP?

Autonomy

Beneficence

Nonmaleficence

Fidelity → Show loyalty, dedication and advocacy, based on the virtue of caring.

Justice

Paternalism

Totality/Integrity

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## Ethical principles of nursing: how do they relate to ACP?

Autonomy

Beneficence

Nonmaleficence

Fidelity

Justice

Paternalism

Totality/Integrity

**Treat all patients fairly and equally, based on equal and fair distribution of resources; considering benefits and burdens.**

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## Ethical principles of nursing: how do they relate to ACP?

Autonomy

Beneficence

Nonmaleficence

Fidelity

Justice

Paternalism

Totality/Integrity

**When appropriate or necessary, make decisions for the patient based on medical knowledge and experience to act in patient's best interest.**

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## Ethical principles of nursing: how do they relate to ACP?

**Autonomy**

**Beneficence**

**Nonmaleficence**

**Fidelity**

**Justice**

**Paternalism**

**Totality/Integrity**

**Consider the entire person when deciding on therapies, treatments, medications.**

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## Survey Question:

If your patient, dying of lung cancer, asks you not to tell her family about her prognosis, which ethical principle **most strongly** guides your actions?

A. **Nonmaleficence**: it would cause your patient mental anguish to tell her family, and you want to avoid that

B. **Autonomy**: your patient has the right to make decisions, including who her information is shared with

C. **Fidelity**: you must remain loyal to your patient and keep commitments to her by promising not to tell

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Ethical obligation to loved ones of your patient

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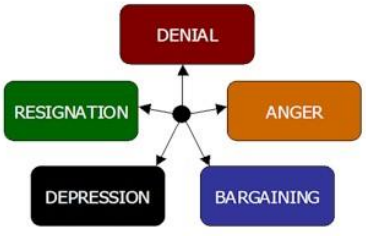



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## Emotional Distress

- 2005 study - 80% of caregivers exhibited symptoms of PTSD at end-of-life of loved one

  Azoulay, Pochard, Kentish-Barnes, et al., 2005

- 1/3 of surrogate decision makers experienced stress, guilt, and other upsetting emotions ... lasting for months - even years

  Wendler, 2011

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## Survey Question:

Which best describes **your** obligation to the people caring for your patient?

A. None (or very little) – the patient is the only one you need to care for
B. It extends just to teaching them to care for their loved one
C. B, + offering emotional support to them as long as it doesn't interfere with the care for your patient
D. B, + offering personalized support as you understand that if they are struggling, it will adversely affect your patient

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## Emotional Distress can be minimized with ACP

- Give patients and family members the opportunity to start preparing emotionally and mentally for death
- Alleviates the burden of decision-making for their loved ones, allowing them to focus on the patient
- Shown to lessen grief and depression among survivors

Detering, et al., 2005

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With an Advance Care Plan

- patients and families talk about wishes ahead of time
- promotes involvement in decision-making

ACP in EHR at all care sites

- Encourage consistent treatment if transitions are necessary

ACP discussions with care teams

- Easier decision-making as values and outcome preferences are known and documented

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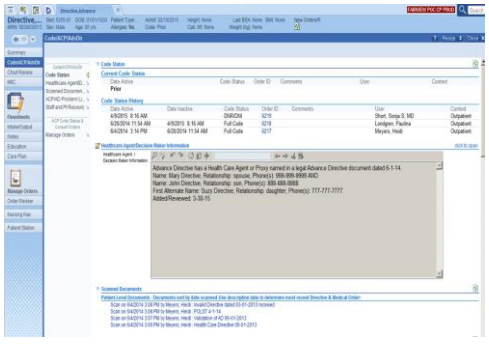
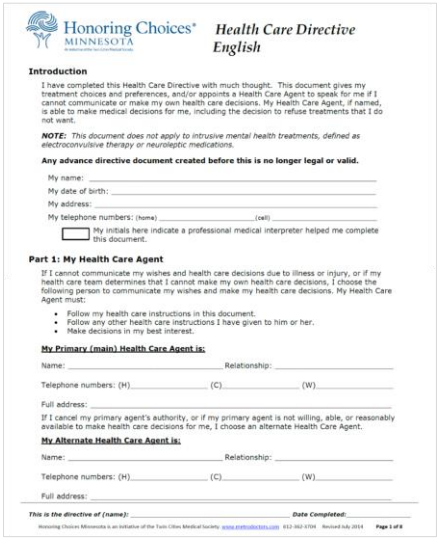
DOCUMENTATION





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HIPAA PERMITS DISCLOSURE TO HEALTH CARE PROVIDERS AS NECESSARY FOR TREATMENT

MINNESOTA
**Provider Orders for Life-Sustaining Treatment (POLST)**

*Follow these orders until orders change. These medical orders are based on the patient's current medical condition and preferences. Any section not completed does not invalidate the form and implies full treatment for that section. With significant change of condition new orders may need to be written. Patients should always be treated with dignity and respect.*

LAST NAME | FIRST NAME | MIDDLE INITIAL

DATE OF BIRTH

PRIMARY MEDICAL CARE PROVIDER NAME | PRIMARY MEDICAL CARE PROVIDER PHONE (WITH AREA CODE)

**A** CHECK ONE — **CARDIOPULMONARY RESUSCITATION (CPR)** *Patient has no pulse and is not breathing.*

- ☐ **Attempt** Resuscitation / CPR (Note: selecting this requires selecting "Full Treatment" in Section B).
- ☐ **Do Not Attempt** Resuscitation / DNR (**Allow Natural Death**).

*When not in cardiopulmonary arrest, follow orders in B.*

**B** CHECK ONE (NOTE REQUIREMENTS) — **MEDICAL TREATMENTS** *Patient has pulse and/or is breathing.*

- ☐ **Full Treatment.** Use intubation, advanced airway interventions, and mechanical ventilation as indicated. Transfer to hospital and/or intensive care unit if indicated. All patients will receive comfort-focused treatments.
  **TREATMENT PLAN:** Full treatment including life support measures in the intensive care unit.
- ☐ **Selective Treatment.** Use medical treatment, antibiotics, IV fluids and cardiac monitor as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). Transfer to hospital if indicated. Generally avoid the intensive care unit. All patients will receive comfort-focused treatments.
  **TREATMENT PLAN:** Provide basic medical treatments aimed at treating new or reversible illness.
- ☐ **Comfort-Focused Treatment (Allow Natural Death).** Relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Patient prefers no transfer to hospital for life-sustaining treatments. Transfer if comfort needs cannot be met in current location.
  **TREATMENT PLAN:** Maximize comfort through symptom management.

**C** CHECK ALL THAT APPLY — **DOCUMENTATION OF DISCUSSION**

☐ **Patient** (*Patient has capacity*) ☐ **Court-Appointed Guardian** ☐ **Other Surrogate**
☐ **Parent of Minor** ☐ **Health Care Agent** ☐ **Health Care Directive**

**SIGNATURE OF PATIENT OR SURROGATE**

SIGNATURE (**STRONGLY RECOMMENDED**) | NAME (PRINT)

RELATIONSHIP (IF YOU ARE THE PATIENT, WRITE "SELF") | PHONE (WITH AREA CODE)

*Signature acknowledges that these orders reflect the patient's treatment wishes. Absence of signature does not negate the above orders.*

**D** **SIGNATURE OF PHYSICIAN / APRN / PA**

*My signature below indicates to the best of my knowledge that these orders are consistent with the patient's current medical condition and preferences.*

NAME (PRINT) (**REQUIRED**) | LICENSE TYPE (**REQUIRED**) | PHONE (WITH AREA CODE)

SIGNATURE (**REQUIRED**) | DATE (**REQUIRED**)

**SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED.** *FAXED, PHOTOCOPIED OR ELECTRONIC VERSIONS OF THIS FORM ARE VALID.*

Minnesota Provider Orders for Life-Sustaining Treatment (POLST). *www.mnpolst.org* **PAGE 1 OF 2**

**Section A is about CPR**

**Section B is about Goals of Treatment**

***If a section is not completed –***
*default is do everything*

**Section C is about who is involved and how decisions were made** – this was moved from the back to emphasize the importance of this form being a continuation of the ACP process

*Real life case study examples:*

- Patient is on general medical floor; no POLST.
- Code called as BP and sats are dropping rapidly.
- He is in and out of cognitive and verbal ability.
- At one point he is heard to say “no breathing tube” but then loses consciousness.
- Response team determines he lacks capacity and intubates him.

**Survey Question:**

Which do you agree with most?

A. Team did the right thing; since capacity was variable
B. Team did wrong thing, he said “no breathing tube” and that should have been honored, even if it ended in death

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*Real life case study examples:*

- Patient has refusing dialysis for weeks.
- Patient has been told her renal failure is non-reversible.
- Patient is told “dialysis or you will die within 2 days”
- Patient agrees to dialysis.
- Following day, patient refuses dialysis.

**Survey Question:**

Ethics team called in. Which do you agree with most?

A. Dialysis should be withheld as it is non-curative and she has a strong history of refusing
B. Patient must have ongoing right to accept or refuse treatments each time it’s offered

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*Real life case study examples:*

- ER patient is intubated after collapsing at home. New to this system.
- He is admitted to ICU, with no directive/POLST/Agent
- Family arrives several hours later with directive in hand, indicating DNAR, demanding he be extubated and treatments stopped
- Patient is now showing signs of possibly breathing on his own (breathing over ventilator)

**Survey Question:**

Which do you agree with most?

A. As patient is improving, he should be weaned and then asked his current preferences
B. Family's request, per patient's directive, should be honored right away

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*Real life case study examples:*

- Patient, with capacity, states he chooses to voluntarily stop eating and drinking
- Family objects, but patient is clear; staff follows his direction
- Eventually he reaches point of losing capacity, at which point family insists on feeding tube

**Survey Question:**

Which do you agree with most?

A. Staff are obligated to continue to follow patient's direction
B. Family (including legal Agent) must be listened to and feeding tube should be put in, at least temporarily, while efforts are made to find best solution

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**We can do any kind of thing TO you.**
***But SHOULD we?***

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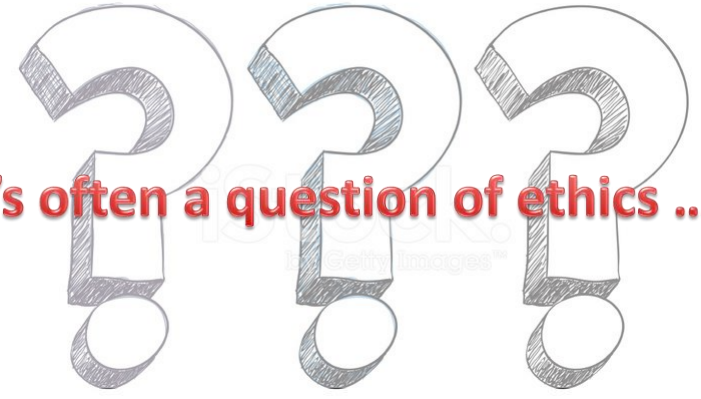

**It's often a question of ethics …**

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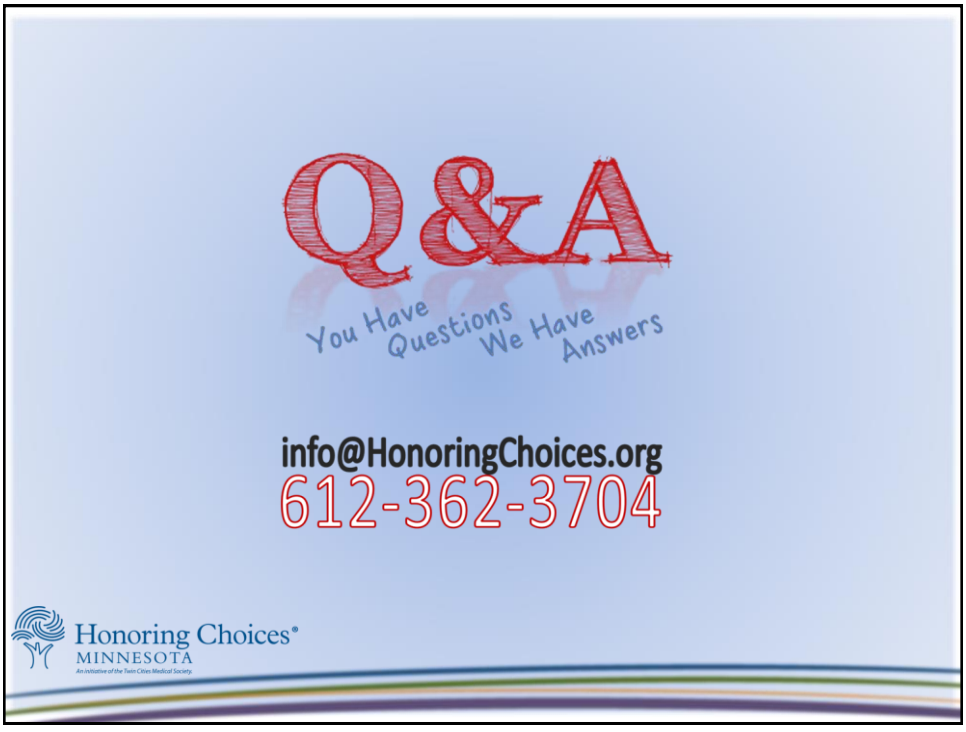


## Questions?

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