Patient Self-Determination: Same Dog, New Twists

CINDY BRUZZESE, MPA, MSB, HEC-C

EXECUTIVE DIRECTOR & CLINICAL ETHICIST – VT ETHICS NETWORK

CLINICAL ETHICIST – UVM MEDICAL CENTER

VERMONT ETHICS NETWORK
Advancing Health Care Ethics

Title of Program: What's Old is New: Fresh Take on Some Classics

Date: May 22, 2024

Title of Talk: Patient Self Determination: Same Dog, New Twists

Workshop #: 21-1

Speaker/Moderator: Cindy Bruzzese, MPA, MSB, HEC-C

Planning Committee Members:

Learning Objective: Articulate recent modifications tot eh VT AD Statute; Appreciate the ethical and legal frameworks within which patient self-determination occurs, Apply shared decision-making principles to advance care planning conversations and documents

Purpose Statement/Goal of this activity: Review new developments in the AD statute and reframe our approach to ACP to improve the quality of our conversations and subsequent documents.

Does the speaker/moderator/planners or reviewers have any relevant financial relationships with Ineligible Companies?

☐ **Yes or** ☒ **No**

If yes, please list their name(s), name of Ineligible Companies, and nature of the relationship:

If yes, were all the relevant financial relationships mitigated: ☐ **Yes or** ☐ **No**

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The University of Vermont designates this live activity for a maximum of __ *AMA PRA Category 1 Credit(s)*™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.

This program has been reviewed and is acceptable for up to __ Nursing Contact Hours.

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This activity was planned by and for the healthcare team, and learners will receive ___ Interprofessional Continuing Education (IPCE) credit for learning and change.

IPCE CREDIT™

Objectives

Articulate	Articulate recent modifications to the Vermont advance directive statute per passage of Act 88
Appreciate	Appreciate the ethical and legal frameworks within which patient self-determination occurs
Apply	Apply shared decision-making principles to advance care planning conversations and documents

What is meant by Patient Self-Determination?

Idea that every adult has the right to make decisions regarding their health/health care, even if those decisions may seem unwise or are contrary to medical recommendation

Encouraging adults to engage in decision-making and the consequences of their decisions, and to be self-governing

Captured by the ethical principle of autonomy – obligation to respect a patient's right to be self-determining and to make decisions in accordance with their goals and values

Ethical Framework

Decision-Making Capacity & Ability

- Understand
- Appreciate
- Reason
- Choice

Accurate and Truthful Information

Informed Consent/Refusal

Voluntariness

Legal Framework

Patient Self Determination Act (PSDA) of 1990

Federal law requiring that hospitals and other specified types of health care organizations participating in Medicare and Medicaid programs inform patients of their right under existing State law to accept or refuse medical or surgical treatment and to formulate advance directives.

Vermont Law

18 V.S.A. § 9700

- Vermont law recognizes the **fundamental right of an adult to determine the extent of health care the individual will receive**, including treatment provided during periods of incapacity and at the end of life.

- This chapter (231) enables adults to retain control over their own health care through the use of advance directives, including appointment of an agent, directions regarding health care, DNR/COLST orders and disposition of remains.

14 V.S.A. § 3075

- A person whose right to make medical decisions has been restricted via guardianship but who has the capacity to make a specific medical decision, retains the right to make that decision.

How does this look in real time?

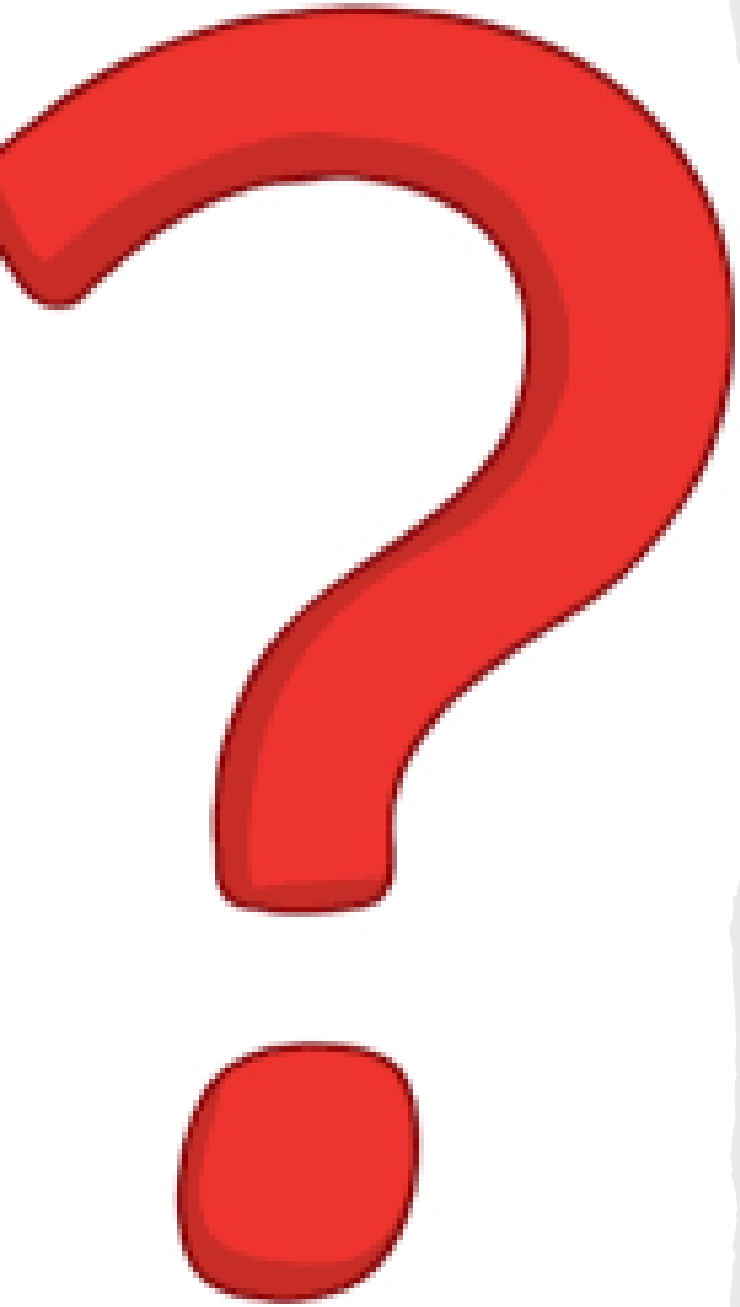
Clinicians and patients, or their surrogates, work together to make health care decisions

Clinician is the expert surrounding medical information and treatment options

Patient is the expert surrounding their goals values, preferences and quality of life

Operates on a continuum

Shared Decision-Making



Ahead of Time

- Advance Care Planning
  - Plan for the “What if’s….."
  - Learn what matters to patients, so the care and treatment they receive aligns with what they value
  - Helps us to provide treatments FOR patient that can achieve their goals and priorities and avoids doing things TO patients by default
  - Requires us to inquire about their understanding
  - Clarifying medical information and **providing context and meaning**
  - Being truthful about what is and is not possible
  - Capturing the outcome of these conversation in advance directives and/or DNR/COLST orders

- Quality of the **conversation** often correlates with the quality of the care or the degree of conflict

More clarifications…

- Conversation first – documentation after (whenever possible)
- Not always possible for patients to build their own burger. Not all combinations of treatments work together—even for those with discerning palates.
- Nuance and/or inconsistency is navigable in an advance directive and should be expected
- Nuance and/or inconsistency is a problem in a DNR/COLST given its emergency applicability
- DNR/COLST is not merely a tool for documenting code status and using it as such is problematic
- Choose your tool wisely

Advance Directives vs DNR/COLST Orders

ADVANCE DIRECTIVE

Preference-based document *completed by a capacitated patient* to guide **future** medical decisions.

- Typically nuanced document requiring discussion, context and interpretation.
- Only a person with decisional capacity can complete/update one.

DNR/COLST

Outcome of shared a decision-making process; medical order *completed by a clinician,* requires informed consent, and is intended to guide **current** treatment decisions.

- Based on patient's *current medical condition* **and** their *goals and values*.
- Consent can be provided by someone other than the patient.

When Patient's Lack Capacity

Health Care Agent

- No limits—all medical decisions that the patient could make if they had capacity, in accordance with patient's goals and values. [18 VSA §9711(4)]

Guardian

- Determined by the court order. Limits to authority for foregoing LST, refusals, change of residence. [18 VSA §9711(4)] and [14 VSA § 3075]

Family/Friends

- Statute silent
  - Exception - consent for hospice [18 V.S.A. § 9710] and DNR/COLST [18 V.S.A. § 9731]

Remember….

Emotional support for surrogate decision-makers without clarity about legal and ethical obligations owed to the patient, opens to the door for potential misunderstandings that the surrogate has a decision to make about the patient's clinical course of care when….

THEY MAY NOT

What Do You Say?

- Patient expresses desire for incompatible treatments (i.e. wants CPR but says they never want to be intubated)
- Family in disagreement with AD and challenges validity of the document saying their loved one didn't have the ability to decide
- LTC facility states they must have a DNR/COLST order to accept patient, but patient has no limitations of treatment
- Patient's guardian and health care agent disagree about needed medical decision

When Advance Directive is Activated

- Agent has authority to make decisions, **in accordance with patient's wishes**
- **Agent does not have authority to override prior decisions made by the patient at a time of capacity**
- Patients without capacity may suspend or revoke their advance directive, including designation of their agent
- Patient **without capacity** may **object to treatment** and treatment may not be provided unless (VT §9707):
  - Patient has a **Ulysses clause** in their advance directive and the agent authorizes overriding the objection
  - Patient will suffer serious and irreversible **bodily injury or death** if care is not provided within 24 hours

Ulysses Clause

Waiver of Right to Request or Object to Future Treatment (18 V.S.A. § 9707)

(h)(1) An advance directive executed in accordance with section 9703 of this title may contain a provision permitting the agent, in the event that the principal lacks capacity, to authorize or withhold health care over the principal's objection.

NAME _____ DOB _____ DATE _____

PART 6: WAIVER OF RIGHT TO REQUEST OR OBJECT TO FUTURE TREATMENT

I hereby give my agent the authority to consent to or refuse the following treatment(s) over my objection if I am determined by two clinicians to lack capacity to make healthcare decisions at the time such treatment is considered:

1. **I *do* want** the following treatment to be provided, even over my objection, at the time the treatment is offered: _____

   I do *not* want the following treatment, even over my request for that treatment, at the time the treatment is offered: _____

2. I give permission for my agent to agree to have me admitted to a designated hospital or treatment facility even over my objection.

   _____ Yes _____ No

3. I give my agent permission to agree that my release from a voluntary admission for mental health treatment may be delayed even over my objection for up to four days so that a decision can be made regarding whether I meet criteria to be involuntarily committed.

   _____ Yes _____ No

4. I hereby affirm that I am knowingly and voluntarily waiving the right to refuse or request specified treatment at a time of incapacity, and that I understand that my doctor and one other clinician will determine whether or not I have capacity to make health care decisions at that time. I know that I can revoke this part of my Advance Directive only when I have the capacity to do so, as determined by my doctor and at least one other clinician.

Signed: _____ , Principal Date: _____

(Continued next page)

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Treatment Preferences

Permission Goals/Waivers

Signature of Principle

Acknowledgements

Acknowledgement by Agent — I hereby accept the responsibility of consenting to or refusing the treatments specified above, even if to do so would be against the principal's expressed wishes at the time treatment is considered.

Signed: *(Agent)*_____ and *(Alternate)*_____

Print names: _____ _____

Phone: _____ _____

Date: _____ _____

Acknowledgement of principal's clinician — I affirm that the principal appears to understand the benefits, risks, and alternatives to the health care specified above that is being consented to or refused by the principal.

Signed: _____ Title: _____

Facility: _____ Date: _____

Please print name: _____

Acknowledgement by persons who explain Part 6 — I, as the designated person to explain Part 6, affirm that I am an ombudsman, recognized member of the clergy, an attorney licensed to practice in Vermont, or a probate court designee and that I have:

- Explained the nature and effect of this Waiver of the Right to Request or Object to Treatment to the principal, and
- The principal appears both to understand the nature and effect of this provision and to be free from duress or undue influence.
- If the principal is in a hospital at the time of signing, that I am not affiliated with that hospital, and
- I am not related to the principal, a reciprocal beneficiary, or the principal's clergy or a person who has exhibited special care and concern for the principal.

Signed: _____

Position: _____ Date: _____

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Agent Acknowledges & Signs

Clinician Documents Informed Consent & Signs

Explainer Acknowledges & Signs

Goal of Act 88 (H.469)

- To clarify the process for completing a Ulysses Clause provision in an advance directive
- To make permanent remote witnessing and explaining of advance directive documents through live, interactive, audio-video connection or by telephone
- To make permissible the use of digital signature for signing, witnessing and explaining of advance directives

https://legislature.vermont.gov/bill/status/2024/H.469

Explanation & Process Pre-Act 88

- Specify treatments an agent can consent to or refuse over the person's objection
- Statement that person does or does not want the specified treatment, even over their objection.
- Specify wishes related to voluntary or involuntary treatment and release from the treatment facility
- Acknowledge in writing knowingly and voluntarily waiving their right to refuse/receive specified treatment at a time of incapacity
- Agent required to agree and sign the form
- Clinician required to affirm understanding and sign the form
- Ombudsman, mental health patient rep., attorney licensed in VT required to explain nature and effect & sign the form

Clarification of Ulysses Clause Process – Per Act 88

Required parties need not all be present at the same time or on the same day and may sign digitally.
Agent/co-agent/alternate agent need not be in person when signing a Ulysses Clause provision at any time.
First time completion of the clinician consent process and the explainer portion must be completed in person (not remotely).
Future updates to AD with Ulysses Clause, clinician and explainer need not be in person but may fulfill their obligations through the use of live, interactive, audio-video connection only. Not via telephone.

18 V.S.A. § 9707(h)

Specific Changes
(Effective April 1, 2024)

18 V.S.A. § 9703 (Form and Execution)

- Expands witnessing and explaining to include doing so remotely
- Allows for use of digital signature for signing, witnessing and explaining
- Establishes criteria for remote witnessing & explaining:
  - Principal and remote witness must be known to each other
  - Communication for both must take place through a live, interactive audio video connection or by telephone.
  - Witness attests that the principal seems to understand and is completing their document voluntarily
  - The name, contact information of witness and their relationship to the principle must be documented on the form

What Are Your Questions?