Incapacitated Patient Refusals and the Vermont Ulysses Clause

Cindy Bruzzese, MPA, MSB, HEC-C

Executive Director & Clinical Ethicist – Vermont Ethics Network

Clinical Ethicist – UVM Medical Center

Director – Statewide Task Force on Palliative Care

Disclosures

Objectives

- Appreciate the Ethical & Legal Frameworks that Underpin Incapacitated Refusals
- Improve Understanding of How to Support Patients in Completing a Ulysses Clause Provisions (Waiver of the Right to Request or Refuse Treatment)
- Identify Patients for Whom a Ulysses Clause May be Helpful

Setting the Stage

- 82-year-old male with advancing dementia
- Admitted after being found by a neighbor, wandering in the street.
- Has been living at home with his 78-year-old spouse who reports he has become more fearful and paranoid and has been striking out at her. The violent outbursts have become worse since he has been refusing to take his medication (Seroquel), stating that it's "poison".
- Since admission, despite staff trying non-pharmacological approaches, the patient continues to refuse medications, is increasingly unwilling to allow routine care, becomes agitated in the setting of wanting to leave, and has required a one-on-one sitter and intermittent emergency medications to maintain safety.

Ethics Framework

- **Beneficence**-based obligations to promote and protect patients' health-related interests
- Adults with capacity have **an autonomy-based** right to refuse
- Adults who lack capacity retain the right to refuse – right to bodily integrity and noninterference captured the concept of **respect for persons**, an extension of the principle of autonomy.
- Involuntary treatment is the exception to the ethical guideline of **respect for persons** that underpins the fundamental right to refuse
- Uses of force violate the ethical principle of **nonmaleficence**– infringe on individual liberties, violates bodily integrity, breaches trust, fractures clinician patient relationship, can cause enduring trauma, etc.

More About Our Case…

- 6 years ago the patient and his spouse completed an advance directive naming his wife as health care agent as well as financial POA.
- Advance directive was non-specific with respect to overall goals and values but indicated he would not want “extraordinary” measures if he was dying.
- While he is medically stable, since his hospitalization began, his agitation and violent outbursts have worsened. A “Code Green” has been called multiple times.
- His wife cannot manage his behaviors at home. Given his frequent aggressive outbursts and the need for a one-on-one sitter, a nursing home disposition cannot be found.
- Patient is stuck in the hospital—isolated and worsening.
- **What are our obligations to this patient?**

Involuntary Treatment Framework

Vermont statute prohibits **treatment over refusal in the medical context** in all but the following circumstances [18 V.S.A. § 9707(g)]:

- When the patient's advance directive contains a properly executed provision (i.e. Ulysses Clause) permitting the agent to authorize treatment over objection in the event the patient lacks capacity, and the agent authorizes treatment;

OR

- When the patient lacks capacity and "will suffer serious and irreversible bodily injury or death if the health care cannot be provided within 24 hours" and:
  - The patient does not have an agent or applicable provision in an advance directive, or the agent is not reasonably available; or
  - The agent or advance directive authorizes providing the treatment.

Permissible Situations and Ethical Guidelines

When patients **lack capacity and it is emergent** – provide standard of treatment to stabilize (rescue). Once stable, seek assent (or at least lack of refusal) to continue treatment.

For safety of patient, staff or others. Limited timeframe due to infringement on freedom/liberties. Uses of force CAN NOT be the care plan. Seek court review/permission for going restrictions (i.e. emergency temporary guardianship).

Patient dignity and personal hygiene—attention to this need is NOT equivalent to medical treatment. Still obligated to least restrictive and minimally burdensome principles.

Remember: Consider proportionality (i.e. potential for benefit/risk of harm) of any forced treatment and ensure least restrictive/least burdensome approaches and shortest time frame.

What About The Involuntary Hold?

Psychiatric Framework

18 V.S.A. §7504 & §7505

- Patients may be **held involuntarily** for an Emergency Evaluation (EE) when they pose an imminent risk to self or others as a result of a major mental illness.

18 V.S.A §7611:

- No person may be made subject to involuntary treatment unless found to be a person in need of treatment

18 V.S.A §7101:

- **"A person in need of treatment"** means a person with mental illness, and, as a result of that mental illness, their capacity to exercise self-control, judgement or discretion in the conduct of their affairs is so lessened that they pose a danger of harm to self or others.

- Psychiatric medication may be administered over objection with an order from the family court, or as an Emergency Involuntary Procedure to prevent **imminent** risk of **serious** bodily harm to the patient or others.

NO Legal Framework for MEDICAL HOLD

In most states, there is no legal authority permitting a physician to issue temporary hold orders in the absence of mental illness; thus, physicians are left to navigate legally and ethically fraught situations with little guidance and no guardrails. Many physicians look to hospital counsel and ethics committees for assistance in these circumstances, but time is often of the essence, and without clear authority on how to proceed, patients with medical incapacity are at risk of being discharged "against medical advice" (AMA), even when the treating physician has determined that they are incapable of understanding the risks involved in refusing treatment.

Wendi Campbell Rogaliner & Elicia Grilley Green, *Medical Incapacity Without Mental Illness: A Legal and Ethical Dilemma for Physicians*, 18 J. Health Law and Life Sci L. 3 (2023).

Real-time Strategies for Responding to Incapacitated Refusals

- Try, try again—encourage, respectfully persuade, re-offer care at a later time, seek out a new face/different person to offer, etc.
- Redirect
- Get creative - is there a stressor/barrier that can be removed/minimized
- Explore all medically reasonable alternatives
- Negotiate a compromise — is there a middle ground that can be found that the patient will accept (or at least not refuse)

Thinking Upstream

Vermont Advance Directive for Health Care

— LONG FORM —

Prepared by the Vermont Ethics Network

Explanation and Instructions

An Advance Directive is a document you prepare to choose someone as your health care agent or to guide others to make health decisions for you. An advance directive can include instructions about your health care as well as what should happen with your body after you die. Having an Advance Directive helps when you no longer can or no longer wish to make your own decisions. As you begin your Advance Directive, here are some important things to know:

- You have the right to consent to or refuse any medical treatment.
- You have the right to appoint an **agent** to make decisions for you.
- You may use this Advance Directive to share your wishes ***in advance***.
- You may fill out all Parts of this Advance Directive form or just portions of it. For example, you can just appoint an agent in Part 1 and then sign Part 9. If you choose not to appoint an agent, you can skip part 1 and just give instructions in other Parts that you wish to fill out. However, if you fill out any Part of this document, you must also fill out Part 9, as it provides signatures and witnesses to validate the Advance Directive.
- You may use any Advance Directive form or format as long as it is properly signed and witnessed.
- You can revoke or suspend your Advance Directive at any time unless you expressly waive your right to do so.

Everyone could benefit from having an Advance Directive — not just those anticipating the end of their lives. Any of us could have an accident or suffer from an unexpected medical condition. Some of us live with a mental or physical illness that leaves us without capacity at times. Without an Advance Directive, those making decisions for you will not know what your wishes are. Worse still, your family and friends could fight over the care you should get. Help them help you — fill out and sign an Advance Directive.

This Advance Directive has 9 Parts. Fill out as few or as many Parts as you like today. If you want, you can fill out other Parts another day. This is your document: change it as you like so that it states your wishes in your own words. You may cross out what you don't like and add what you want. This form was proposed as an optional model form by the Vermont Department of Health and adopted by the Legislative Committee on Administrative Rules.

Note: For copying and storing purposes only the actual form pages, not the instructions, have consecutive page numbers. When sending copies, you need send only the numbered pages of the form itself.

Ulysses Clause Provision Requirements 18 VSA § 9707(h)

- An agent shall be named in the provision.
- The agent shall accept in writing the responsibility of authorizing or withholding health care over the objection of the patient.
- The clinician shall sign the provision and affirm that the principal appeared **to understand the benefits, risks, and alternatives** of the health care being authorized or rejected by the principal in the provision.
- An ombudsman, a mental health patient representative, attorney licensed in VT, or the Probate Court designee shall sign a statement affirming that they have explained the nature and effect of the provision to the patient and they appeared to understand and be free from duress or undue influence.
    - If the principal is a patient in a hospital when the provision is executed, the ombudsman, mental health patient representative, attorney, or Probate Division of the Superior Court designee shall be independent of the hospital and not an interested individual.

Ulysses Clause Provision Requirements 18 VSA § 9707(h)

- The provision shall specify the treatments to which it applies and include an explicit statement that the principal desires or does not desire the proposed treatments even over the principal's objection at the time treatment is being offered or withheld. The provision may include a statement expressly granting to the health care agent the authority to consent to the principal's **voluntary** hospitalization.
- The provision shall include an acknowledgment that the principal is knowingly and voluntarily waiving the right to refuse or receive treatment at a time of incapacity, and that the principal understands that a clinician will determine capacity.

Long Form – Part 6 Page 1

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)

Specific Treatments

Voluntary Admission

Waiver of Right

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:_____

Part 6 - Page 2

Agent Acknowledgements

Clinician Acknowledgement

Explainer Acknowledgement (if applicable)

Clarification of Ulysses Clause Process (2024)

Required parties need not all be present at the same time or on the same day and may sign digitally.

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)

Utility & Limits of a Ulysses Clause

Situations where a Ulysses Clause may be helpful

- Psychiatric illness as part of Psychiatric AD
- Dementia with behavioral disturbance as addendum to Medical AD
- Permission for Covert Medications
- Operationalizing “do-not-spoon feed” preferences in a Medical AD

Limitations of Ulysses Clause

- Specific treatment focus
- Doesn’t give broad authority to override incapacitated refusals in any context
- Can’t address incapacitated revocation of health care agent
- Doesn’t appear to solve the “medical hold” problem

Take Aways for Incapacitated Refusals

- Uses of force are ethically problematic—cannot be the “plan”, is not sustainable
- Seek patient *assent* or at least their lack of refusal; encourage, redirect, compromise, etc.
- Be proactive with planning and use a Ulysses Clause provision where appropriate
- Minimize burden/harm and be least restrictive
- Involuntary hold under an EE only applicable for psychiatric indications
- Seek authority for ongoing medical hold through petition for emergency temporary guardianship with permission to hold over objection

Food for thought…

- *The Medical Incapacity Hold: A policy on Involuntary Medical Hospitalization of Patients Who Lack Decisional Capacity.* Erik H. Cheung, MD, et.al. Psychosomatics, Volume 59, Issue 2, March–April 2018, Pages 169-176
- *The doctor as jailer: medical detention of non-psychiatric patients*. Charles Kersten, MD, JD. Journal of Law and the Biosciences, Volume 6, Issue 1, October 2019, Pages 310–316, https://doi.org/10.1093/jlb/lsz008
- *Medical Detention of Incapacitated Patients*. Mark W. Newman MD and Carolyn S. Keller, MD, MHA. J Gen Intern Med 39(16):3330–2; 2024. DOI: 10.1007/s11606-024-09010-3
- *Medical Incapacity Without Mental Illness: A Legal and Ethical Dilemma for Physicians*. Wendi Campbell Rogaliner & Elicia Grilley Green, 18 J. Health Law and Life Sci L. 3 (2023)